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ABSTRACT

This monograph, which reports findings from the New Jersey Governor's Council on the Prevention of Mental Retardation, discusses the scope of mental retardation (MR), its causes, identification of people at risk, and prevention methods. The Council cites several cost-effective prevention programs, such as vaccination programs and prenatal care services. Council recommendations to prevent MR before conception and during pregnancy include: counseling for genetic and teratologic defects, developing information on exposure to environmental contaminants, educating persons at risk about alcohol and the unborn, fostering new attitudes about substance abuse, reducing the risk of adolescent pregnancy, and insuring the medically needy. To prevent MR at the time of birth, the Council recommends ensuring full-term births and providing follow-up care for infants with birth defects and infants at risk. Recommendations for MR prevention during childhood include: immunizing against infectious diseases, expanding health services in school settings, encouraging breast feeding, expanding the Special Supplemental Food Program for Women, Infants and Children, providing for public health nutritionists, testing for lead poisoning, teaching parenting skills, improving protection in automobiles and school buses, and creating an Office for Prevention Programs. Numerous statistical tables, some specific to New Jersey and others nationwide in scope, are incorporated throughout the text. (JDD)

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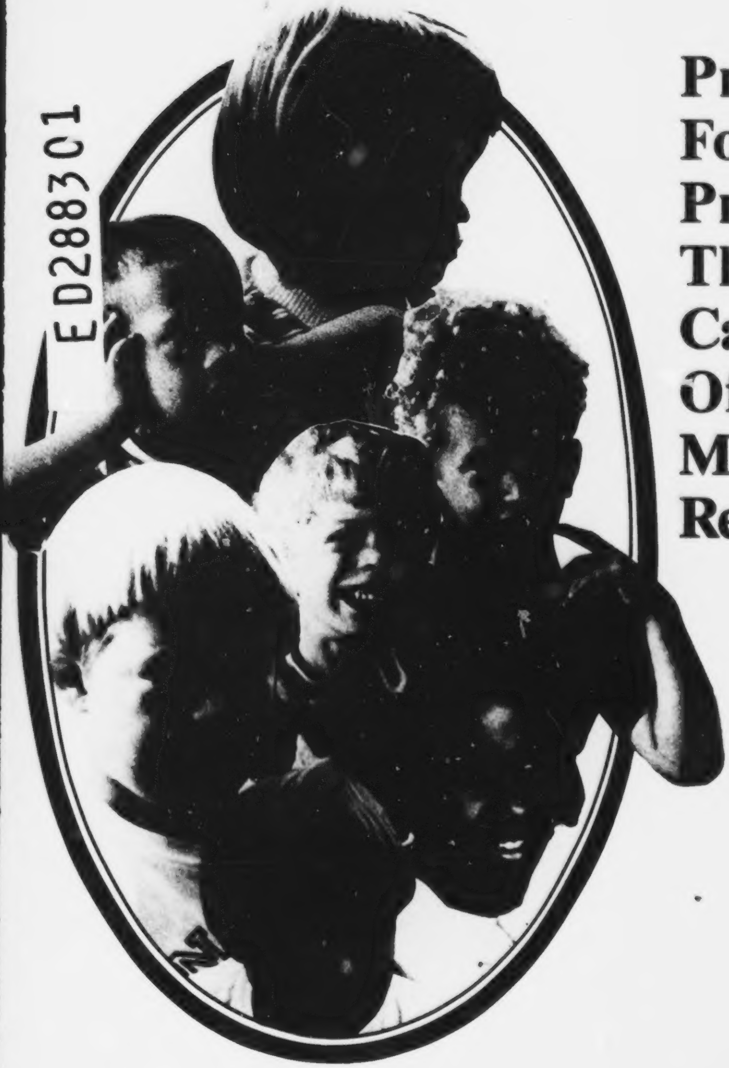

Programs For Preventing The Causes Of Mental Retardation

Governor's Council on the Prevention
of Mental Retardation

New Brunswick, New Jersey
1985

EC 200 772

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NEW JERSEY GOVERNOR'S COUNCIL
ON THE PREVENTION OF MENTAL RETARDATION

Deborah Bye Kean, Honorary Chairperson
Richard Goldberger, Chairperson

PROGRAMS FOR PREVENTING THE CAUSES OF MENTAL RETARDATION

Written for the
Governor's Council on the
Prevention of Mental Retardation

by

Peter S. Oliphant, Ph.D.
Barbara Geiger-Parker
Glenna W. Gundell

with the assistance of
Carol B. Funk

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HONORABLE THOMAS H. KEAN
GOVERNOR OF NEW JERSEY

by the
Association for Retarded Citizens/New Jersey
William Vogt, President
John P. Scagnelli, Executive Director

New Brunswick, New Jersey

1985

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MEMBERS OF THE GOVERNOR'S COUNCIL ON THE PREVENTION OF MENTAL RETARDATION

HONORARY CHAIRPERSON

DEBORAH B. KEAN was born in Wilmington, Delaware and graduated from the Tower Hill School and Bennett College. Before marrying in 1967, she worked as a volunteer for the A. I. Dupont Institute for Crippled Children in Wilmington. Now the mother of three children, she has been a volunteer for St. Barnabas Hospital in Livingston, New Jersey and has taken on the honorary chairmanship of the Governor's Council on the Prevention of Mental Retardation as her first statewide responsibility to the social services.

CHAIRPERSON

RICHARD GOLDBERGER serves as Chairman of the Board of both Garden State Brick Face and Stucco, Inc., and New England Brickmaster, and is a general partner in the Mid-Investment Company. He directs the financial and planning strategies and the boards of these companies. Prior to founding Garden State Brick Face and Stucco, Inc., he was a paratrooper in the United States Army during the Korean War. He is active in philanthropic work, including serving as a member of the Board of Trustees of the Rabbinical College of America. He is a director of the Franklin State Bank and has received numerous awards for his leadership in business and in charitable enterprises, including Man of the Year 1984 from the New Jersey Chapter of the National Association for the Advancement of Colored People and an honorary doctoral degree from the Rabbinical College of America. He is a graduate of Rider College.

COMMISSIONERS

GEORGE J. ALBANESE served as Commissioner of the New Jersey Department of Human Services from 1982 to mid-1985. Among his responsibilities as Commissioner were administering a $3.2 billion budget and providing social services to more than one million New Jersey residents. His current position is President/Chief Executive Officer of Dynasty Homes Ltd. He received a Master's Degree in Public Administration from New York University and a Bachelor's Degree in City and Regional Planning from Rutgers University.

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GEOFFREY S. PERSELAY, ESQ., Acting Commissioner of Human Services, previously served as Chief of Staff in the department. A graduate of the U. S. Capitol Page School and of Hobart College, he received his law degree from Seton Hall University School of Law. While employed in Union county government, he received several achievement awards from the National Association of Counties and the New Jersey Association of Counties.

SAUL COOPERMAN, Ed.D., was born in Newark and educated in the West Orange public schools. After graduating from Lafayette College, he served as a teacher and principal in New Jersey public schools; earned an Ed.D. in 1969 from Rutgers University; became superintendent of schools for Montgomery Township and for Madison, New Jersey; and was appointed Commissioner of Education in 1982. He is an active teacher and has published in the areas of school administration, social change, budgeting, and staff development.

J. RICHARD GOLDSTEIN, M.D., is a physician and an architect with expertise in healthcare planning. Appointed Commissioner of Health in 1982, he is coauthor of Hospital Special Care Facilities; has taught at Columbia University; and has consulted with the National Institute of Health, Veterans Administration, and private corporations. He was a flight surgeon for the United States Air Force, and president of a national health-management consulting firm.

ALFRED A. SLOCUM, ESQ., the Public Advocate, came to the department after more than a decade as a member of the Rutgers University Law School in Newark, where as an associate professor of law, he specialized in real estate and estate law. An East Orange native, he started his professional career as an electronics engineer after being introduced to the field during the Korean War. He has served as chairman of the minority student programs committee at Rutgers, was founder and chairperson of a youth rehabilitation organization in Newark, has served as general counsel of the National Organization of Black Law Enforcement Executives, and is a member of numerous organizations including the National Conference of Black Lawyers and the Puerto Rican Legal Defense and Education Fund.

PUBLIC MEMBERS

STANLEY S. BERGEN, M.D., is President of the University of Medicine and Dentistry of New Jersey and is an active teacher of medicine who has more than 30 years of experience in medicine and administration. He has been honored many times for his contributions to medical education, humanitarian services, and research. More than 12 years of research and publication in metabolic processes have been followed by extensive publication in the delivery of health care and in medical education.

ELIZABETH M. BOGGS, Ph.D., one of the founders of the Association for Retarded Citizens/United States, has been active in the association for three decades, has been national president, and is currently chairman of the New Jersey association's committee on residential services, and a member of its executive committee. She is a Life Fellow of the American Association on Mental Deficiency. She holds a doctoral degree in theoretical chemistry from Cambridge University, and has been awarded two honorary degrees and numerous national and international awards for leadership in mental retardation. She is particularly known for her work in developing public policy and legislation related to developmental disabilities.

JEANNE BROOKS-GUNN, Ph.D., Senior Research Scientist for the Educational Testing Service, has been a program director and university instructor, specializing in infant, child, and adolescent health and development. Trained in human learning and development at the University of Pennsylvania and Harvard University, she is coauthor or editor of five books on human development and is preparing a book on early adolescence to be published by Harvard University Press. She has published some 70 articles and chapters, has presented as many papers at conferences, and is a member of a number of national and state boards and advisory committees.

SEYMOUR CHARLES, M.D., co-founder of the Physicians for Automotive Safety, is a pediatrician in private practice; Associate Clinical Professor of Pediatrics and of Preventive Medicine at New Jersey Medical School, University of Medicine and Dentistry of New Jersey; and Chief of Voluntary Staff for the Department of Pediatrics, Newark Beth Israel Medical Center. Known for his advocacy for automobile and school bus safety, he has testified and published widely in this area. He is active in professional associations and serves on the advisory board of directors for two health organizations. He received his medical degree from New York University.

CECILE DICKEY, Executive Director of Concerned Parents for Head Start, Paterson, built that organization into a $1.5 million operation that services 394 children in eight sites. She is active in a wide range of community services: former Commissioner of the Paterson Board of Adjustment; Chairperson of the New Jersey Anti-Lead Poisoning Coalition; Chairperson of the National Head Start Association's membership committee and member of its public relations committee; and Chairperson of the Paterson Coalition for Public Accountability. Most recently, as Chairperson of Concerned Parents for Better Housing, she created a $2.5 million Sojourner Truth housing development of 47 townhouses in Paterson. She has received many awards for her outstanding community services.

BEVERLY SILLS GREENOUGH, since 1979 General Director of the New York City Opera. is an internationally known soprano. She has appeared with every major opera company and orchestra in the United States, has a repertoire of more than 70 roles, and is one of the foremost interpreters of nineteenth-century bel canto. She is national chairman of the March of Dimes' Mothers' March on Birth Defects and was awarded the Presidential Medal of Freedom.

CAESAR P. KIMMEL, former Executive Vice President of Warner Communications, Inc., is a specialist in mass communication and motivation. A graduate of Rutgers University, he is a major shareholder in the Warner Corporation.

RICHARD J. KOGAN, Executive Vice President, Schering-Plough Corporation, is a specialist in the worldwide pharmaceutical business. He is a graduate of the New York University Graduate School of Business Administration, and a director of the Accountants' Network of America, the Summit Trust Company, and the Pharmaceutical Manufacturers' Association. He is a member of the President's Committee on Mental Retardation.

PETER LEVINE is President of Levcom, a major real estate development company based in West Paterson that owns and operates shopping centers in many states across the country. He has been a member of the New Jersey Sports and Exposition Authority, which has operated the Meadowlands Sports Complex since 1978, and presently is Treasurer and Chairman of its Personnel Committee. He is actively involved in philanthropic and civic activities including being a founder of the Albert Einstein College of Medicine, a member of the Prime Minister's Club of Israel, a recipient of the Israeli Leadership Award and of the Justice Louis D. Brandeis Humanitarian Award, and an honorary life member of the New Jersey Policeman's Benevolent Association.

MARY LOTZE, R.N.C., P.N.P., is Director of the Laurie Neurodevelopmental Institute at Rutgers Medical School, and has directed programs in child evaluation, special therapy, and the developmentally handicapped. A graduate of St. Vincent's Hospital School of Nursing, she is a certified pediatric nurse practitioner, teacher, consultant, and member of many professional societies. As a volunteer for health planning, she has served on advisory committees for the attorney general, the public advocate, and the New Jersey State Nursing Association, among others. She has been responsible for mobilizing nearly $1 million in grants and awards and has been a trainer, community-services planner, and participant in continuing education for 15 years.

RICHARD L. MASLAND, M.D., was director of a monumental study of prevention of and research into mental retardation: Mental Subnormality (published with T. Gladwin and S. Sarasen). He later became director of the National Institute of Neurological Diseases and Stroke; and head of the Department of Neurology, College of Physicians and Surgeons, Columbia University. Currently, he consults on convulsive disorders. As director of the National Commission on Control of Epilepsy and its Consequences, he guided the collection of data and the preparation of its report. He is nationally recognized as an authority in neurological conditions, model programs, and program planning. He presently serves as President of the World Federation of Neurology.

SUSANN R. ORA, has extensive experience in animal training and care, which she uses as a teacher of innovative career paths in animal care for developmentally disabled children in the Morris county schools. She is a graduate of Upsala College, and, as a past member of the President's Committee on Mental Retardation, she chaired a committee on Indian affairs to determine the incidence of mental retardation among native American children. She is a former officer of the Association for Retarded Citizens of Sussex County and served on several state and local advisory boards, including the Family Court Advisory Board and the Committee on Special Education, Kean College.

PETER ROBERTS has a wide range of experience in public information, mass media, and mass motivation, owing to some 25 years in broadcasting in New Jersey and New York. He voices commercials; narrates slides, films, and filmstrips; and conducts radio/TV interviews and seminars. He has served on the boards of health care groups.

ALFONSO A. ROMAN, M.Th., Secretary for Social Welfare Ministries of the United Church Board of Homeland Ministries, gives technical assistance to organizations that serve the poor and leads national groups. He holds a Master's Degree in Theology, and a Master's Degree in Human Resources and Manpower Development from the New School for Social Research, New York. He began work as an agricultural chemist in Puerto Rico, where he organized a successful ministry among drug addicts in prison that developed into programs in the departments of health and justice, and where he directed an ecumenical training center. As director of the Metropolitan Ecumenical Ministry in Newark and, later, of the Puerto Rican Congress of New Jersey, he organized projects in daycare, education, manpower, housing, research, and business development and extended the role of advocacy for Spanish-speaking persons in the state and the nation.

THOMAS D. SAYLES, JR., is Chairman, President, and Chief Executive Officer of the Summit Bancorporation, which he joined after 12 years with Manufacturers Hanover. A graduate of New York University Graduate School of Business, he is a trustee of Dartmouth College, Drew University, the Independent College Fund of New Jersey, Overlook Hospital Foundation, and the Summit Area Public Foundation and a member of various professional banking associations.

JOHN P. SCAGNELLI, Executive Director of the Association for Retarded Citizens/New Jersey, has a distinguished career in social services that developed out of his directing community programs for the Boys Clubs of Newark and of America and for the Children's Aid Society of New York City. A graduate of New York University and of Columbia University, he holds the B.S., B.S.M.E., M.A., and A.B.D. degrees. He was Director of Research for the Boys Clubs of America and was instrumental in conducting several national research projects for which he received the Bronze Keystone award for his achievement, the highest award presented by Boys Clubs of America. He is a board member of many social-services programs, and serves as a member of the Governor's Juvenile Justice Advisory Committee, the Association for Rehabilitation Facilities, the Maternal and Child Health Advisory Committee, the Advisory Committee to the Public Advocate, and the National Conference of Executives of Associations for Retarded Citizens. Recipient of two Presidential awards for outstanding, innovative programs of national significance, he also has received awards from the Joseph P. Kennedy Foundation, the United Community Fund of Essex and West Hudson, the United Way of Central Jersey, the Association for the Developmentally Disabled of New Jersey, the American Camping Association, the Occupational Training Center for the Handicapped, and St. John of God School, among others.

ANTHONY D. SCHOBERL, is Chairman of the Board of Franklin Bancorp and Franklin State Bank. A graduate of the American Institute of Banking, his career in finance has spanned 45 years. Previously he has served as board chairman for St. Peter's Medical Center, the Easter Seal Society of New Jersey, the New Brunswick Housing Authority, and the New Jersey Bankers Association. Some of his current civic activities include acting as Chairman of the Board of Trustees for Vianney Convalescent and Day Care Center, and as board member for Georgian Court College and the Rutgers Community Health Plan. He has received awards from the State of Israel, the New Jersey Easter Seal Society, and various local organizations.

LAWRENCE T. TAFT, M.D., is Professor and Chairman of the Department of Pediatrics, Rutgers Medical School of the University of Medicine and Dentistry of New Jersey. He has held appointments at various New Jersey hospitals, the Albert Einstein College of Medicine, and the Bronx Municipal Hospital Center. He is a member, trustee, or advisor to many national, state, and local operating and fund-raising agencies and planning programs; a fellow of international and national professional associations; and the recipient of many awards for outstanding services in pediatric health. He has published widely in pediatric medicine.

NANCY TRINGALI has been employed by the March of Dimes Defects Foundation for the last ten years. Currently serving as Coordinator of Field Services for the New York Market Area, she previously has worked as chapter executive director and director of Walkathons. A graduate of Trenton State College, she is a member of the New Jersey Chapter of the National Society of Fund Raising Executives.

RON VRBA, is the Executive Vice President/General Manager of Bozell & Jacobs, Inc., Union, New Jersey, an advertising agency that provides a full range of advertising and public relations services through twelve domestic offices in four geographic areas and through international operations. He is a graduate of the University of Nebraska and was a teacher until 1959 when he went into advertising. He has been active in civic and state activities such as the United Way, March of Dimes, Water Conservation, the Port Authority Advisory Council, the World Trade Institute Advisory Board, the New Jersey Turnpike Region Environmental Enrichment Project, and numerous other organizations.

DAVID W. WINIKUR, Ed.D., is Executive Director of PACE Clinical Services, a private consulting firm located in Princeton, New Jersey, which provides consulting and clinical services to schools, public agencies, and the private sector. A graduate of Pennsylvania State University, he holds an M.Ed. and Ed.D. degree from Temple University, and is certified in school administration. He has been director of the Department of Pupil Personnel Services, New Brunswick Public Schools; and of the Bureau of Pupil Personnel Services, New Jersey Department of Education. A specialist in research, he holds various academic appointments; represents state and national professional associations; and is widely published in minority studies, counseling, and educational administration.

LEON J. ZIMMERMAN operates a consulting firm that specializes in governmental and public relations and serves as counsel and legislative lobbyist for major statewide associations, private corporations, and businesses. He is a graduate of Montclair State College and attended the Penn State University Graduate School of Journalism and the American Press Institute of Columbia University, was a journalist for 12 years with The Record of Hackensack, and has been honored for his reporting of public affairs. Among other civic activities, he has served on the board of the Association for the Advancement of Mental Health; the Education Commissioner's Advisory Council on the Handicapped; the New Jersey Developmental Disabilities Council; and the Association for Retarded Citizens.

PHILIP R. ZIRING, M.D., is Chairman of the Department of Pediatrics and Director of the Developmental Disabilities Center at Morristown Memorial Hospital. A graduate of New York University School of Medicine who completed his pediatric training at New York University-Bellevue Hospital Medical Center, he is known for his work in identification and management of children with congenital rubella and was engaged in the original research leading to the development of a vaccine to prevent rubella. He has been a medical consultant to a number of programs that serve handicapped children and adults, including the New York State Office of Mental Retardation and Developmental Disabilities; Pennsylvania Division of Mental Retardation; and the New Jersey Division of Developmental Disabilities. He has been Medical Director at the Lexington School for the Deaf, the New York Institute for the Education of the Blind, the Staten Island Developmental Center, and the Roosevelt Hospital University Affiliated Facility for the Developmentally Disabled.

ALTERNATES

HERBERT D. HINKLE, Esq., has headed the Division of Advocacy for the Developmentally Disabled of the New Jersey Department of the Public Advocate since 1976. He has been involved in a wide range of litigation concerning right to treatment and protection from harm, voting rights, sterilization, education, handicap discrimination, and the delivery of life-sustaining treatment. A graduate of Rutgers University School of Law, he chairs a special subcommittee on the handicapped for the New Jersey Bar Association and is a member of the Developmental Disabilities Council.

EDDIE C. MOORE, Director of the Division of Developmental Disabilities, New Jersey Department of Human Services, began his career working with the mentally disabled at the Bronx Psychiatric Center in New York State. In 1972, he joined the staff of Bernard Fineson Developmental Center as Treatment Team Leader and later was advanced to the position of Chief of Service. In 1978 he became Director of Program Operations for the Office of Mental Retardation and Developmental Disabilities, New York-Long Island Region, and in 1979 was appointed associate commissioner. Appointed Director of the Division of Mental Retardation, in New Jersey in 1981, he is responsible for the development of programs and services to people with mental retardation, cerebral palsy, epilepsy, autism, and various neurological impairments. He is a graduate of Queens College and Fordham University. He has received many distinguished awards. Among them are the Humanitarian Award from the Association for Retarded Citizens/Bergen-Passaic, the Service Award from the Parents and Friends Association of Vineland, the Bertha Baily Award for his work with Foster Grandparents, and the Distinguished Service Award from the United Negro College Fund. He is a board member of Harlem Dowling Adoption Services and was appointed Court Monitor by the United States Federal Court, District of Connecticut, in the CARC vs Thorne Consent Decree involving the right to treatment for the mentally retarded at Mansfield Training School.

JEFFREY V. OSOWSKI, now Director of the Division of Special Education, New Jersey Department of Education, has been director of special services and of pupil personnel in local New Jersey school districts, a staff psychologist in correctional programs, and a teacher of the handicapped. He is a graduate of Kean College and is completing doctoral work at Rutgers University in thinking and creativity.

LEAH Z. ZISKIN, M.D., M.S., Assistant Commissioner of the Division of Local and Community Health Services for the New Jersey Department of Health, is responsible for federal and state programs which provide services to the public aimed at preventing disease and disability. She has been with the Department of Health for 14 years and previously has served as Director of Parental and Child Services and Director of Research and Evaluation. Having earned her Medical Degree from Temple University and a Masters Degree in Preventive Medicine from Thomas Jefferson University, she is Board Certified in Public Health. She has been honored by the New Jersey Health Officers Association, the National Hemophilia Foundation, and the New Jersey Family Planning Forum for her work in public health. She has served as a consultant to the federal Office on Maternal and Child Health and has presented numerous papers at the American Public Health Association.

TASK FORCE CHAIRPERSONS

MICHAEL MCCORMACK, Ph.D., Professor of Pediatrics and Chief of Genetics, of the School of Osteopathic Medicine, University of Medicine and Dentistry of New Jersey, created and directs a statewide registry of environmental teratogens that are associated with birth defects. He has published extensively in human genetics and mental retardation, including Prevention of Mental Retardation and Other Developmental Disabilities (1980), a nationally known source book. He was Chairman of the prevention conference organized by the Association for Retarded Citizens/New Jersey.

ROBERT TUCKER, Ph.D., Deputy Director of the Division of Science and Research, New Jersey Department of Environmental Protection, is a research scientist who specializes in environmental toxicology. He is a member of the American Association for the Advancement of Science and of the International Association of Ecologists. A graduate of the University of California and of Duke University, he received the United States Public Health Services fellowship award. He received the award for outstanding scientist of the year from the Department of Environmental Protection.

ANN M. WILSON, A.C.S.W., is Coordinator of the New Jersey Network on Adolescent Pregnancy, and specializes in organizing community support, education, awareness, and prevention activities around adolescent issues. She is the recipient of many awards and has been both a social worker with the Division of Youth and Family Services, New Jersey Department of Human Services, and the executive director of a community mental health center.

STAFF

PETER S. OLIPHANT, Ph.D., Director, is an anthropologist who went to Gabon, West Africa, as a Peace Corps Volunteer, after graduating from Georgetown University. Having trained in egyptology at the Oriental Institute of the University of Chicago, he conducted fieldwork for the Field Museum of Natural History in the Republic of the Camerouns, received his Ph.D. in anthropology from the University of Chicago, and went on to teach at Bates College, the New School for Social Research, and New York University. From his work as an editor for Demography and as a technical writer, he has experience in research and publication. As Research Associate for the New Jersey Commission on Children's Services and for the Governor's Committee on Children's Services Planning, he has written on policy analysis and program development. He has additional graduate training in psychology and in human resources management. Among other social activities, he volunteers as Chairperson of the New Jersey Anti-Lead-Poisoning Coalition.

BARBARA M. GEIGER-PARKER, Research Associate, holds a graduate degree from Rutgers University and has specialized in survey and technical research. Experienced in managing survey-research projects, conference planning, and editorial work, she began her career as a social worker for the Delaware Division of Social Services, where she managed a caseload of clients with employment barriers. She has published in the fields of role discrimination and political careers, organization directories, and bibliographies.

GLENNA W. GUNDELL, Program Associate, formerly president of the New Jersey PTA, has volunteered for more than 17 years in community services and is now a Vice President for Region II on the Board of Directors of the National PTA. She is an instructor of neurologically- or emotionally impaired children for the Piscataway Board of Education; an appointee to the Governor's Task Force on Child Abuse and Neglect; and chair of the National PTA's project on prevention of drug and alcohol abuse.

CAROL B. FUNK, Administrative Assistant, has more than 20 years of experience in secretarial work, typesetting, and word processing. A graduate of New Brunswick High School, she has worked in the areas of real estate, public opinion polls, and social services. She has chaired many committees of the North Brunswick Women's Club and is active in several church groups.

TASK FORCES OF THE GOVERNOR'S COUNCIL ON THE PREVENTION OF MENTAL RETARDATION

TASK FORCE ON THE BIOMEDICAL CONDITIONS OF MENTAL RETARDATION

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Michael McCormack, Ph.D.
Chief of Genetics, School of Osteopathic Medicine,
University of Medicine and Dentistry of New Jersey, Camden

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Pediatric Consultant, Newark Health Department

Carolyn Crawford, M.D.
Neonatal Director, Southern New Jersey Perinatal
Cooperative, Camden

Josef Eisinger, Ph.D.
Molecular-Biophysical Research, Bell Laboratories
Murray Hill

Marvin Gottlieb, M.D.
Director, Institute of Child Development, Hackensack
Medical Center

Chris Hansen, M.D.
Pediatric Consultant, Division of Youth and Family Services
Department of Human Services

John Harrigan, M.D.
Director, Maternal-Fetal Medicine, St. Peter's Medical
Center, New Brunswick

Robert Jaslow, M.D.
Medical Director, New Lisbon Developmental Center

Robert Johnson, M.D.
Associate Professor of Clinical Pediatrics,
University of Medicine and Dentistry of New Jersey
Newark

Barbara Kern Chief, Special Child Health Services,
New Jersey Department of Health

Mark Lewis, Ph.D.
Department of Psychiatry, School of Osteopathic Medicine
University of Medicine and Dentistry of New Jersey
Camden

Benjamin Mojica, M.D.
Director, Communicable Disease Control Services,
New Jersey Department of Health

Thomas Power, M.D.
Children's Seashore House, Atlantic City

Lucille Schechter
Genetics Counselor, St. Barnabas Hospital, Livingston

Samuel Thompson, Ph.D.
Acting Director, New Jersey Department of Public Health,
Clinical Laboratory Improvement Services

Donald C. Van Dyke, M.D.
Clinical Director, Children's Seashore House,
Atlantic City

Ilana Zarafu, M.D.
Division of Neonatology, Newark Beth Israel Medical Center

Leo Zuckerman
Director, Regulatory Compliance,
Ortho Diagnostic Systems, Inc., Retired
Somerville

TASK FORCE ON THE ENVIRONMENTAL CONDITIONS OF MENTAL RETARDATION

CHAIRPERSON

Robert Tucker, Ph.D.
Deputy Director, Division of Science and Research
New Jersey
Department of Environmental Protection

CO-CHAIRPERSON

Leah Z. Ziskin, M.D., M.S.
Assistant Commissioner, Community Health Services,
New Jersey Department of Health

MEMBERS

Ronald Altman, M.D.
Assistant Commissioner, Division of Epidemiology and
Disease Control, New Jersey Department of Health

Edmond Duffy
Coordinator, Accident Prevention and Poisoning Control,
New Jersey Department of Health

Nancy Hall, Ph.D.
Environmental Scientist, New Jersey Department of Health

Judith Klotz, D.P.H.
Environmental Scientist, New Jersey Department of Health

Michael Knox
Director, Planning and Operational Support,Division of
Developmental Disabilities, New Jersey
Department of Human Services

R. Alexandra Larson
Director, Governor's Committee on Children's Services
Planning

Dennis McDonough
Coordinator, Health Projects, New Jersey
Department of Health

Steven Marcus, M.D.
Director, New Jersey Poison Information and
Education Center, Newark
Newark Beth Israel Medical Center

Ciro Scalera
Executive Director, Association for Children
of New Jersey, Newark

S. I. Shahied, Ph.D.
Assistant Commissioner, Division of Public Health,
New Jersey Department of Health

Kathy Strassberger, RN, MSN, ANP
Coordinator, Developmental Disabilities Center
Morristown Memorial Hospital

TASK FORCE ON THE SOCIAL CONDITIONS OF MENTAL RETARDATION

CHAIRPERSON

Ann Wilson
Coordinator, New Jersey Network on Adolescent Pregnancy,
Rutgers University School of Social Work
New Brunswick

MEMBERS

Martha Bolds
Director, Community Action Day Care, Paterson

Bernadette Countryman, RN
New Jersey Nursing Association

John P. Delaney, Ed.D.
Superintendent, Woodbridge Developmental Center

Gary Engel
Executive Assistant to the Director,
Woodbridge Developmental Center

Mary Guess Flamer
Education Program Specialist, New Jersey
Department of Education

Audrey Gotsch, Ph.D.
Director, Office of Consumer Health Education,
University of Medicine and Dentistry of New Jersey

Laurie Horn, MSW, CSW
Director, Division of Mental Health Services,
East Orange General Hospital

Carol Kaslander
Program Specialist, Division of Alcoholism, New Jersey
Department of Health

Roberta Knowlton
Executive Director, New Jersey Network for Family Life
Education, Rutgers University School of Social Work
New Brunswick

Lula R. Linder
Executive Director, AD House, Inc., Newark

Marilynn Malony, M.Ed., RN
Director, Special Services, Camden Board of Education

Amy Meltzer, M.D., MPH
Coordinator, Maternal and Child Health,
New Jersey Department of Health

Betsy Riegel
Middlesex County Supervisor,
Division of Youth and Family Services
New Jersey Department of Human Services

Lewis Ware, MSW
President,
New Jersey Association of Black Social Workers

Cynthia Wilks, MSRD
Scope Head Start, Nutrition Coordinator

Leo Zuckerman
Director, Regulatory Compliance,
Ortho Diagnostic Systems, Inc., Retired
Somerville, New Jersey

TASK FORCE ON PUBLIC INFORMATION ON PREVENTION OF MENTAL RETARDATION

CHAIRPERSON

Peter Roberts
Newscaster

MEMBERS

Mary Ann Ahearn
School Psychologist
Vice President
Association for Retarded Citizens/New Jersey

Charlene Brown
Director, Office of Public Information,
New Jersey Department of Human Services

Karl Greiner
Director, Public Information, Association for Retarded
Citizens/New Jersey
New Brunswick

Thomas Hagy
Public Information Officer,
New Jersey Department of Health

John Harrigan, M.D.
Director, Maternal-Fetal Medicine, St. Peter's
Medical Center, New Brunswick

Marybeth Kohut
Program Director, Childhood Immunization Education,
New Jersey Hospital Association

Robert Mahon
Coordinator, Community Education, Division of Youth
and Family Services, New Jersey Department

Kathy McNamara
Community Service Specialist, University Affiliated
Facilities, Rutgers Medical School
Piscataway

Krystal Odell
Director, Community Education, Division of Developmental
Disabilities, New Jersey Department of Human Services

Paul Shelly
Assistant Coordinator, Community Education Unit,
Division of Youth and Family Services,
New Jersey Department of Human Services

Niecee Singer, M.S.
Genetics Coordinating Counselor,
Morristown Memorial Hospital

RECOGNITION

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The deliberations of each task force are summarized in the recommendations. While the staff of the council wrote the final versions (and is responsible for any errors they may contain), we are especially obliged for the extra work given us by members who drafted recommendations.

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CHAPTER 1

SUMMARY

MENTAL RETARDATION

Mental retardation is a condition that begins in early childhood. Persons with mental retardation have a "significantly subaverage" intellectual functioning and a limited ability to lead an independent life. This condition appears in the developmental period of childhood and is life-long and irreversible.

There Are Many Mentally Retarded People

Some 2-3 percent of our citizens probably will be mentally retarded before they reach adulthood. "Profound, severe, and moderate" mental retardation so impair a person that lifelong personal care or supervision are needed. These degrees of retardation may affect 30,000-40,000 persons in New Jersey. "Mild" mental retardation permits learning basic skills (such as reading and arithmetic) and living semi-independently or independently. Mild mental retardation is the most common type: as many as 60 percent of mentally retarded people are mildly mentally retarded.

Mental Retardation Has a High Cost

Some of the costs of disability include care and maintenance of those who are unable to care for themselves, and productivity lost by those who do not contribute to the economy. Beyond these economic costs are the incalculables: pain and suffering, dependence on others, and social stigma.

People are valued as human beings in our society, regardless of the presence of handicapping conditions. Preventing and alleviating disabilities are ways that we choose to express the value that we place on each person as an individual. Now, in the present state of our knowledge, mental retardation is not curable. So, prevention of the condition whenever possible takes on a high priority.

The dollar costs of mental retardation are very large. These costs include both remedial programs for persons who are affected by mental retardation and "early intervention" programs to minimize the effects of conditions that have been identified in the very young. The need for some portion of all these programs might have been averted if earlier precautions were taken. Therefore, some of the expenditures can be chalked up to the failure to provide primary prevention.

We cannot consistently add up all the dollar costs per person, for each service, to the state or to the federal government. But we can say that remedial programs cost over $400 million each year (plus undeterminable millions for general assistance to persons who are unemployed or difficult to employ owing to mild mental retardation). In addition to this, early intervention programs cost over $75 million.

PREVENTING MENTAL RETARDATION

Mental retardation can be prevented. While it is a common condition, many of the causes arise from environmental, organic, and social conditions that affect health. Everyday, however, we learn more about how to protect our health.

Protecting our health by means of *preventive* health programs, will increasingly have to become a priority. As Governor Kean has said, health-care costs are the single most inflationary factor in the economy today. As our population, social complexity, and living standards increase, all health-care resources will be increasingly strained. We must learn to use our limited resources more carefully. Preventing a condition before it occurs is most often the most "cost effective" use of resources.

Prevention Programs Succeed

Strategies for preventing mental retardation have already shown success. Some conditions have been nearly eliminated (congenital rubella, retardation from phenylketonuria and congenital hypothyroidism, neonatal jaundice, and measles encephalitis). Other conditions have been reduced (for example, morbidity from prematurity). And significant efforts are now underway for other conditions (neural tube defects, fetal alcohol syndrome, prenatal screening, lead poisoning, and injuries to the brain from automobile accidents).

Governor Kean's Council on the Prevention of Mental Retardation

The President's Committee on Mental Retardation has been giving high priority to prevention in the last five years. Federal efforts are important, but the level of government most critical to success is the state. Governor Kean rose to this challenge in 1984 when he established his Council on the Prevention of Mental Retardation.

The Association for Retarded Citizens/New Jersey

John P. Scagnelli, Executive Director of the Association for Retarded Citizens/New Jersey, suggested in 1983 that the governor establish a program to prevent mental retardation. In December 1983, the association and the Department of Human Services submitted a proposal to the governor. This came with the support of George J. Albanese, Commissioner of the Department of Human Services, and of Eddie C. Moore, Director of the Division of Developmental Disabilities of that department.

The governor responded with all resources. In his message to the New Jersey legislature on January 10, 1984, the governor announced his intention to appoint a council to develop a statewide plan for prevention. This showed the sincere interest of the highest level of government. On March 6, 1984, the governor named Mrs. Deborah B. Kean honorary chairperson of the council. Mrs. Kean's interest and participation have given the program wide public appeal.

The Council and its Task Forces

The governor's Executive Order Number 72 set out the task: study and evaluate services and mobilize citizens and agencies in cooperative working relationships. The membership of the council brings together volunteers who represent many sectors of the state. There are four department commissioners; there are persons from the health professions, business, and industry; and there are parents of retarded children. This makes it possible for the public and private sectors to plan together.

The appointed members of the council asked 80 professionals to lend their expertise to the council's work. These people joined in four "task forces" and drew on their extensive experience in providing services in public and private agencies. Over a year's time, they reviewed the biomedical, environmental, and social, causes of mental retardation, and they considered how to convey information about prevention most effectively to the public.

THE COUNCIL'S FINDINGS

The Causes of Mental Retardation Lie in the Earliest Periods of Life

Known and suspected causes of mental retardation operate primarily in the early periods of life.

> *Before conception and during pregnancy,* the parents' genetic systems, environmental contaminants, diseases and infections, and social conditions affect reproduction and the development of the fetus.
>
> *At birth,* there are complications of delivery and conditions of the newborn (such as prematurity or low birth weight) that are known to affect the brain and to increase the risk of impairment.

During childhood, diseases and illnesses, malnutrition, lead poisoning, abuse and neglect, and accidents may result in mental retardation.

These periods of life can be used to make a checklist of the known and suspected causes of mental retardation. Some of these are shown in the accompanying figure.

1. **BEFORE CONCEPTION AND DURING PREGNANCY:**

A. Organic conditions

Chromosomal abnormalities
Genetic abnormalities
Congenital infections and maternal diseases

B. Environmental conditions

Environmental contaminants
Alcohol
Drugs
Radiation

C. Social conditions

Adolescent pregnancy
Inadequate prenatal care

2. **AT THE TIME OF BIRTH:**

Premature birth
Birth complications

3. **DURING CHILDHOOD:**

Diseases and infections
Malnutrition
Lead poisoning
Abuse and neglect
Accidents
Poisoning

Many in New Jersey Are At Risk

Data are often not adequate to permit us to report specific numbers of persons who may be at risk of mental retardation from each of these causes. But findings suggest that these numbers may be very large. To give just a few examples:

1. BEFORE CONCEPTION AND DURING PREGNANCY:

Less than one-half of women at risk for hereditary disorders used genetic conditions counseling services in 1983.

There were 1,287 consultations (1982-1984) for exposures to environmental agents that can affect reproductive cells or the fetus.

As many as 135,000 women have alcohol-related problems. Many of these women are in their childbearing years, when even moderate use of alcohol has been associated with mental retardation in newborns.

Before the 10th grade, 82 percent of pupils report using alcohol; 41 percent report using marijuana; and 20 percent report using amphetamines. These legal and illegal substances affect the health of the unborn — even drugs so socially accepted as smoking. (About 30 percent of youth and adults are smokers.)

There were 4,246 births to women aged under 18 years (1983). Pregnancy in adolescence increases the risks of premature birth, low birth weight, birth complications, and birth defects.

250,000 people with incomes below poverty are not eligible for medicaid, the primary resource for prenatal and maternity care, among low-income women.

2. AT BIRTH:

About 15,000 births occur each year after inadequate prenatal care.

Serious congenital malformation and complications that are known to affect the brain occur in 2-3 percent of each year's 98,000 births. Screening at birth identified nearly 4,000 cases of asphyxiation, sepsis, and seizures in the most recent year.

3. DURING CHILDHOOD:

Thousands of preschoolers are found to be unvaccinated when they enter school.

Only 45 percent of eligible children received pediatric care under the medicaid program known as EPSDT (Early Periodic Screening, Diagnosis, and Treatment).

Only 37 percent of eligible women and children received nutritional supplements under programs designed to provide for low-income, high-risk cases.

Among children who were tested for lead poisoning in 1984, 1,317 were found to be lead burdened. Just 25 percent of children who live in areas where there is a high-risk of lead poisoning were tested in 1984.

Almost 5,000 cases of child abuse and more than 8,000 cases of neglect were documented in 1983.

Head injury is the most common reason for which children are admitted to hospitals: 15,000-20,000 admissions per year in New Jersey.

Prevention Programs Are Highly Cost Effective

Investing in prevention programs is a recent effort, but there is evidence that the benefits save enough to be cost effective in dollars, even without taking the "cost effectiveness" in human terms into account.

1. BEFORE CONCEPTION AND DURING PREGNANCY:

Prenatal Care

Advocates estimate that Ohio saves $4 for every $1 invested; the Harvard School of Public Health concluded in 1978 that $1 spent on prenatal care would save $3 in hospitalization; and the Virginia Prenatal Services Advisory Council concluded that Virginia could save $49.8 million in medicaid by providing better prenatal services.

Prenatal and Neonatal Testing

Massachusetts estimates that screening for genetic disorders such as trisomy 18, Down's syndrome, Hunter's syndrome, and Tay-Sachs disease will save $2-$20 per dollar of cost.

The Centers for Disease Control, Atlanta, estimate that screening for fetal neural tube defects would cost $2 million to screen 100,000 women; but the total economic benefits would exceed $4 million.

2. AT BIRTH:

Preventing Premature Births

California's "Creasy" program reported cost savings in lower physicians' fees and hospital fees to be $11,240 per birth in 1984.

3. DURING CHILDHOOD:

Following Up Infants at High Risk

Savings of $573,500 to California's medicaid program for the first two years of follow-up were reported for a project that cost $557 per infant.

Immunization

The most dramatic cost benefit demonstrated to date has been the outcome of vaccination programs. Ten years of immunization against measles have saved the United States $1.3 *billion* by averting 24 million cases, saving 2,400 lives, and preventing 7,900 cases of mental retardation.

Nutrition

A study of births in Massachusetts shows that for every $1 spent on the program that provides food supplements to women and children, $3 in medical expenses were saved.

We Already Know How to Prevent Many Conditions

We already know how to limit diseases and environmental contamination; how to test the unborn, the newborn, and the very young for hereditary disorders; how to give good prenatal care and address the signs of premature birth; and how to ensure proper child rearing, nutrition, health, and safety .

New Jersey now has a wide network of both public and private resources with potential for prevention in its public and private agencies and in the goodwill of its citizens.

Programs for Those Who Are Most at Risk

We need to bring these resources together to plan more effective ways to deliver prevention services to each year's 98,000 New Jersey newborns and their families. More effective ways of providing services must be developed; services that now exist must be coordinated and expanded; models from other states must be collected and evaluated; and new types of services must be provided.

The council addresses the need to coordinate resources by recommending *programs*, rather than making broad statements on policy. Each recommendation is addressed to *reach the people who are most at risk*. Most of the recommended programs are *ready to be put in place*. Others are already in place but *need to be expanded*. Each recommendation, finally, includes a rough estimate of the costs of the recommended program.

Some of the major recommendations are these:

1. BEFORE CONCEPTION AND DURING PREGNANCY:

Expand Genetic and Teratologic Counseling

Provide equal access to counseling services and reach out to people who are known to have genetic conditions. Develop a data base for consultation, referral, follow-up, and study of statistical data

Develop Information on Exposure to Environmental Contaminants

Implement laws and regulations, educate the public, label products, and organize sources of information on the distribution of diseases in the population

Educate Persons at Risk about Alcohol and the Unborn

Organize agencies to identify women at risk, train professionals in the signs of risk, and staff community-based programs with alcoholism counselors

Foster New Attitudes about the Use and Abuse of Substances

Support legislation that provides disincentives for the use of "social" drugs, provide comprehensive health education in the schools, and require insurance contracts to cover treatment programs

Reduce the Risk of Adolescent Pregnancy

Create a task force on adolescent pregnancy and expand services for family planning and family-life education

Insure the Medically Needy

Provide the optional medicaid program that extends coverage for pregnant women for prenatal care and for persons under 21 for preventive health care

2. AT THE TIME OF BIRTH:

Ensure Full-Term Births

Educate parents and professionals in the risk for pre-term birth and reach out to women who are at highest risk

Follow Up Infants with Birth Defects and Infants at High Risk

Register all infants with birth defects and infants born under high-risk conditions to ensure referral, treatment, case management, home-health visits, and pediatric evaluation. Increase follow-up programs through the state's perinatal centers, and use the information to evaluate health-care programs and assess new risks

3. DURING CHILDHOOD:

Immunize against Infectious Diseases

Improve programs to extend immunization to all children; organize the system so as to prepare for possible use of new vaccines as they are developed; develop additional educational programs; improve the capacity of diagnostic laboratories to use the most up-to-date methods; and develop research projects to identify and control infectious diseases

Establish a Task Force on Expanding Health Services in School Settings

Encourage free-standing clinics in school settings in districts where there are high numbers of families eligible for medicaid

Encourage Breast-Feeding, Expand the WIC Program, and Provide for Public-Health Nutritionists

Set mimumum standards for hospitals to encourage breast-feeding. Consider matching the federal contribution to the Women, Infant, Child nutrition program. Require local health departments to provide the services of a public-health nutritionist

Test Every Child in High-Risk Areas for Lead Poisoning and Abate the Hazards of Lead

Alert parents to the hazards of lead, remove lead hazards from sources in dwellings and elsewhere, and test and treat every child in high-risk areas of the state

Teach Parenting Skills through Family Life Education

Develop a curriculum and distribute this to 2,000 educators in the state to improve education in early childhood and parenting skills

Improve Protection in Automobiles and in School Buses

Require the use of seat belts in the rear seats of vehicles, provide loaner seats for infants, and begin a statewide public-information campaign. Equip all newly purchased school buses with safety belts and with seats with backs of a minimum height of 28 inches

Identify People Who Are Disabled or At Risk and Encourage New and Expanded Services

Determine the extent of mental retardation among low-income families, and document needs for services among special groups, such as those who are affected by both mental retardation and emotional disturbance. Encourage private agencies to survey the people they serve and hospitals to provide innovative prevention programs such as new modes of testing for neonatal jaundice and community education programs

An "Office for Prevention Programs"

A review of prevention plans from other states shows that New Jersey is a leader in a growing national movement. And the council is convinced that considerable work remains to be done.

Providing an Office for Prevention Programs would fulfill the need for a long-range, comprehensive plan in the most effective way precisely because it would promote coordination of services by making new programs available and seeing that innovative programs get the support that they need.

> *Stimulate new and expanded services.* — Public and private agencies need to be *encouraged* to provide prevention programs. There already is a strong interest owing to the need to use our resources ever more judiciously. Agencies need to learn about model programs and to be provided the opportunity to develop their own.
>
> *Coordinate public and private agencies.* — Each program requires that mechanisms be developed by coordinating services among the departments and agencies outside government.
>
> *Facilitate legislative and executive action.* — Many programs will require executive and legislative action. There must be central coordination directed from the highest levels of government.
>
> *Develop public information and community education.* — Public information and community education campaigns need to be developed from the ground up. In most cases, the needed materials, curricula, media, and advertising programs have to be invented wholesale; and in most cases, public and private agencies do not have the resources to do this on their own.
>
> *Encourage research.* — There should be additional research. Although there are literally hundreds of known causes of mental retardation, in many instances the causes remain obscure. Even when a cause is discovered, it does not always follow that a practical means of prevention can be devised without further study.

The most effective way to develop an office for prevention programs is to locate it in the office of the governor, rather than of (or even in) a state department. This will give the visibility and the objectivity that are required. Moreover, such an office should be a permanent office of government.

Thousands of state and private agencies offer services over a wide range of needs and clients. An office for prevention programs can determine which of the services of these agencies can be mobilized for prevention; encourage cooperation among them; help develop common data bases and research programs; and assess and publicize the benefit costs of prevention programs.

CHAPTER 2

THE GOVERNOR'S COUNCIL ON THE PREVENTION OF MENTAL RETARDATION

PREVENTION PROGRAMS

Public health has been measurably improved in our century thanks to prevention programs. Water purification, inoculations, and screening and testing for vitamin deficiencies are some of the activities that contribute to prevention that we now take for granted.

Prevention strategies are put into place when there is a significant number of cases and a body of knowledge about the conditions. Further, people have to be prepared to design a strategy and to develop a system to deliver the services; and the public has to be prepared to accept the prevention effort (Guthrie 1983).

Because of the growth of interest in prevention, the President's Committee on Mental Retardation has been giving high priority to prevention in the last five years. Federal efforts are important, but the level of government most critical to success is the state. Governor Kean met this challenge in 1984 when he set up his Council on the Prevention of Mental Retardation.

ASSOCIATION FOR RETARDED CITIZENS/NEW JERSEY

It was the need for services for preventing mental retardation and the knowledge that they can be put in place that led John P. Scagnelli, Executive Director of the Association for Retarded Citizens/New Jersey, to propose that the governor establish a program to prevent mental retardation. In December 1983, the Department of Human Services and the Association for Retarded Citizens/New Jersey submitted a proposal to the governor. This came with the support of George J. Albanese, Commissioner of the Department of Human Services, and of Eddie C. Moore, Director of the Division of Developmental Disabilities of that department.

The proposal explained that a program of prevention would have to affect many services over a *statewide* range. For this to be effective:

> Support would be needed from the highest level of government, because interest would have to be clearly demonstrated on a basis that would have high visibility for public appeal.
>
> Commitment would be needed to the concept of some kind of permanent structure in state government for prevention.

GOVERNOR THOMAS H. KEAN

The governor responded with all resources: sincere interest at the highest level, high visibilty, and a request to design the structure for prevention.

First, in his message to the New Jersey legislature on January 10, 1984, Governor Kean announced his plan to appoint an "advisory council" on mental retardation to develop a statewide plan for prevention. Locating the prevention effort in a governor's council demonstrates the commitment of the highest level of government.

Second, on March 6, 1984, the governor named Mrs. Deborah B. Kean Honorary Chairperson of the Governor's Council on the Prevention of Mental Retardation. The participation of the governor's wife, her personal interest and commitment, and her participation in meetings of the council gave the efforts an added dimension.

Executive Order No. 72

Governor Kean's Executive Order No. 72, which set up the council, sets out the task of designing services and mobilizing support in six points:

DESIGN SERVICES

1. Study the prevention of mental retardation and develop a comprehensive plan for prevention
2. Evaluate current prevention activities in New Jersey and other states
3. Develop mechanisms to facilitate detection of the causes of mental retardation

MOBILIZE SUPPORT

4. Mobilize citizens and community agencies in a strong effort for prevention
5. Foster cooperative working relationship among the relevant agencies
6. Define and convey to the public information on the prevention of mental retardation

Membership of the Council

The governor established a council that brings together volunteers who represent many sectors of the state. There are four department commissioners, who represent education, health, human services, and the public advocate. There are persons from the health professions, business, and industry. And there are parents of retarded children. This makes it possible for the public and private sectors to plan together.

The "Task Forces" of the Council

In addition to the appointed members of the council, some 80 professionals were asked to lend their expertise to the council's work. These people, who have extensive experience in providing services in public and private agencies, met in four task forces. The task forces covered biomedical, environmental, social, and public information issues.

These task forces provided the background, data, and information on programs for remediation and prevention out of which the recommendations that the council presents in this report were constructed.

The Council's Recommendations

The council chose to make its recommendations in the form of suggested programs. Each recommendation suggests where a specific program can be situated in a specific agency. Further, the programs recommended are those designed to reach people who are most at risk (especially potential parents, the unborn, the newborn, and the young). Some of these are recommendations for expansions of programs already in place; others are for new programs. In each case, a rough estimate of potential costs is given.

A COMMON DISABILITY THAT WE CAN PREVENT

Since mental retardation is so common a disability, planning for the future must stress prevention. As our population, political and social complexity, and living standards increase, all health-care resources, not just those for the mentally retarded, will be increasingly strained.

Yet, we already know how to prevent many of the causes of mental retardation: how to give good prenatal care and prevent premature birth; how to test the unborn, the newborn, and the very young for hereditary disorders; how to ensure proper childrearing, nutrition, health, and safety; and how to limit diseases and environmental contamination.

What is more, there already is a wide network of both public and private resources with potential for prevention in New Jersey's public and private agencies and there is the goodwill of its citizens.

What is needed is to bring these resources together to plan more effective ways to deliver prevention services to each year's 98,000 New Jersey newborns and their families. More effective ways of providing services must be developed; services that now exist must be coordinated and expanded; models from others states must be collected and evaluated; and new types of services must be provided.

THE STRUCTURE OF THIS REPORT

It was the work of the task forces and of the council together that produced the comprehensive plan outlined in our report to the governor. This report:

Reports on the scope of mental retardation (Chapter 3)

Reviews the known and suspected causes of mental retardation and the numbers of people who may be at risk (Chapter 4)

Presents a plan of implementation that provides for a permanent office for prevention programs (Chapter 6)

Summarizes and develops a rationale for each of its recommendations (Chapters 7-22)

Explores the need for reaching out to persons who are most at risk and for providing new and expanded services (Chapter 23)

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CHAPTER 3
THE SCOPE OF MENTAL RETARDATION

DEFINITION OF MENTAL RETARDATION

Mental retardation is a disabling condition (not a discrete disease entity) that becomes manifest in childhood as limited intellectual functioning combined with limited social competence.

Criteria used to determine the diagnosis of mental retardation are standardized intelligence tests and scales of "adaptive behavior," that compare what a person can do to the norms established for persons of the same age.

Although not all states use the same definition (because of the needs of different programs [Frankenberger 1984]), New Jersey programs follow the definition of mental retardation set by the American Association on Mental Deficiency (1983).

> Mental retardation refers to significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period.

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"General intellectual functioning" is assessed by one or more of the individually administered general intelligence tests developed for the purpose of assessing intellectual functioning.

"Significantly subaverage intellectual functioning" is approximately intelligence quotient (IQ) 70 or below.

"Adaptive behavior" is the effectiveness or degree with which individuals meet the standards of personal independence and social responsibility expected for age and cultural group.

"Developmental period" is the period of time between birth and the 18th birthday.

CLASSIFICATIONS OF MENTAL RETARDATION

Mentally retarded persons are commonly classified according to the degree that their intellectual and adaptive functioning impairs their ability to lead independent lives, as shown in the accompanying list.

CLASSIFICATIONS AND MENTAL RETARDATION (American Association on Mental Deficiency)

Classification	Range of IQ	Adaptive Behavior
Mild mental retardation (educable)	50-55 to about 70	Basic functional academic skills (reading, arithmetic) and independent or semi-independent living
Moderate mental retardation (trainable)	35-40 to 50-55	Limited learning, self care, and simple vocational skills
Severe mental retardation	20-25 to 35-40	Dependency on continuing supervision and assistance in living
Profound mental retardation	Below 20-25	Life-support care for major biological problems (for example, oxygen or special feeding)

SOURCE: American Association on Mental Deficiency 1973

RATES OF MENTAL RETARDATION

Many people are affected by mental retardation. It is generally estimated that 2-3 percent of the population could be identified as mentally retarded before they reach adulthood. Recently, a study of over one-half million consecutive live births, through an excellent, population-based health registry in British Columbia, reported the age-specific prevalence rates shown in Figure 3-1 (Baird and Sandovnick 1985).

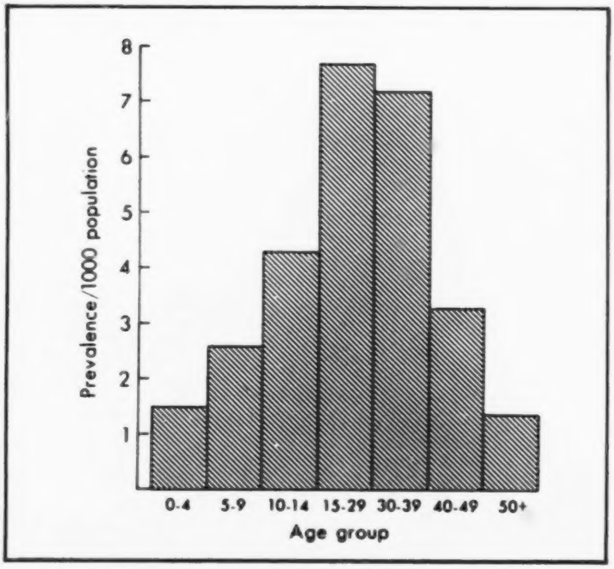

Figure 3-1. — Age-specific prevalence rates for all levels of mental retardation in the British Columbia population at year end 1981*

SOURCE: Baird and Sandovnick 1985

***The definition of mental retardation used in this study includes "borderline" (IQ 70-90) and "mild" (IQ 50-69).**

Mental retardation is, by definition, a condition that arises before conception and during pregnancy, at birth, or during development up to age 18. The highest age-specific rates of prevalence used to be among adolescents because mental retardation affects school achievement. More recent studies suggest that mental retardation is more prevalent in the whole age range of people born after World War II. More persons with mental retardation from this age group were likely to survive into adulthood than were persons in the age group born before or during the Depression.

Applying the findings from British Columbia to our population base suggests that about 10 percent of infants who are born each year in New Jersey will eventually need special education during their early years and that 0.5 to 1 percent may need some on-going services in their adult years, as a result of mental retardation.

Profound, Severe, and Moderate:
30,000-40,000 in New Jersey

Profound, severe, and moderate retardation that may so impair a person that lifelong personal care or personal supervision are needed is found in a fractional percentage of the population. This translates into about 30,000-40,000 in New Jersey; about one third of whom are on the rolls of the Division of Developmental Disabilities of the Department of Human Services, as shown in Table 3-1.

Table 3-1. — **Retarded persons in developmental centers and in the community, known to the Division of Developmental Disabilities, New Jersey Department of Human Services, 1983 and 1977**

Placement	Year	
	1983	1977
Total	10,356	7,970
In developmental centers	5,811	7,932
In the community		
Own homes	2,943	38
Skill development homes	560	0
Group homes and supervised apartments	587	38
Unsupervised apartments and other licensed facilities	455	0

SOURCE: New Jersey Department of Human Services n.d.

NOTE: In recent years, more children and adults have been identified who are living with their own families. The numbers shown in Table 3-1 do not include all mentally-retarded children who are in special education classes or registered with Special Child Health Services in the Department of Health, or adults who receive services from the Division of Vocational Rehabilitation of the Department of Labor or from county and state divisions of the public welfare.

Mental Retardation is More Common at the Higher Levels of Functioning

The broader the definition, of course, the more common we find mental retardation. If "learning disabilities" or "cognitive impairment" are included in the definition, the category of persons with mental retardation is quite large, for example.

The milder forms of mental retardation, which permit more independence than the more difficult (profound, severe, and moderate) forms, are more common than the more difficult conditions. For instance, Taft (1980) has estimated that in a population defined as retarded, 60-70 percent fall into the mildly retarded range.

Technology Increases the Numbers of Persons with Mental Retardation in the Population

The proportion of persons with mental retardation in the population is growing, owing to increases in survivorship. We now can save more persons who formerly would have been lost. Such medical technology as neonatal intensive care ensures that some infants now survive who would have died earlier. More who would have survived with a disability now grow up without a handicap, of course. But there is a growing pool of survivors of special nursery care who are at risk of mental retardation but whose disability may not show up until some years after they have left the special nursery. This was reported by a recent study of access to developmental services.

> Sophisticated fetal monitoring techniques and neonatal intensive care have increased the number of surviving low-birth-weight infants. The large majority of these babies develop normally; others will have developmental delays or disabilities and will need [early intervention] services if they are to reach their full potential. State agencies are raising questions about identification, referral, and tracking systems for high-risk infants. Health and education providers, as well as parents, are...asking questions about what services are needed and how services are coordinated (Project ACCESS 1985).

Mental Retardation Is More Common among Low-income Populations

It is generally accepted that a significant portion of mild mental retardation is attributable to some of the same causes as are more serious cases but without the same clear clinical signs. At the same time, it is recognized that milder forms of mental retardation are also attributable to social and environmental conditions that most affect low-income populations in the cities and in impoverished rural areas (Fotheringham, Hambley, and Haddad-Curran 1983; Cantalician Foundation n.d.; Norfolk State College 1977).

EXPENDITURES FOR MENTAL RETARDATION

The calculable costs of disability include care and maintenance for those who are unable to care for themselves, as well as productivity lost by those who do not contribute to the economy. Beyond these economic costs are the incalculables: pain and suffering, dependence on others, and social stigma (Ireys and Magreb n. d.). Mental retardation is a source of economic loss to the nation and of distress to the families in which it occurs. It means a reduction in human potential for self-direction, productivity, and social contribution.

People are valued as human beings in our society, regardless of handicap. Preventing and alleviating disabilities are expressions of the value that we place on each person as an individual. Since, in the present state of our knowledge, mental retardation is not curable, prevention of the condition whenever possible takes on a high priority.

On the one hand, persons who are moderately, severely, or profoundly retarded are the most likely to be socially and or economically dependent and to require some extensive, direct special services throughout their lives at a relatively high per-capita cost. On the other hand, by virtue of their larger numbers, persons with milder forms of retardation represent high aggregate "opportunity costs" — productivity lost when persons who could have earned an average income through life are reduced to marginal status.

Recently, efforts have been growing to increase the productivity and employability of adults who are retarded, including those with moderate and severe retardation, as well as those with mild retardation.

Annual Public Expenditures

COSTS FOR REMEDIAL PROGRAMS

The most conspicuous recurring annual costs for programs that attempt to remediate the conditions of mental retardation in New Jersey are shown in the accompanying tabulation. (Available data do not permit us *consistently* to provide costs per person, per service, to the state, or to the federal government.)

Department	**Dollars**
Department of Human Services	
Division of Developmental Disabilities	
Disabilities	
Federal and state funds for clients who are retarded	311 million
Division of the Public Welfare	
Federal, state, county and municipal costs of the AFDC (Aid to Families with Dependent Children) program and of general assistance for needy, unemployed persons who are mildly retarded but who are not considered disabled enough to qualify for Supplemental Social Security Income	(undetermined)
Social Security	
Federal benefits for adults under provisions for benefits in childhood disability	30 million
Supplemental Security Income	
Federal benefits for children and adults	27 million
State and county supplementary benefits	5 million
Department of Education	
Federal, state, and local funds to public schools for trainable and educable students and for "day training"	51 million
Department of Labor	
Division of Vocational Rehabilitation	
State funds for retarded clients in extended work programs and for short-term rehabilitation into competitive employment	9 million

ANNUAL COSTS FOR SPECIAL PROGRAMS AND FOR EARLY INTERVENTION

New Jersey has already instituted several special programs of early intervention for children who exhibit developmental delays or who are born under conditions that put them at high risk of mental retardation. These may be regarded as forms of "secondary prevention," but in the sense that need for them might have been averted by earlier precautions, some of the expenditures can also be chalked up to the failure to provide primary prevention. Some indicators of these costs as experienced in New Jersey are listed here in the accompanying tabulation.

DEPARTMENT	DOLLARS
Department of Health	
Cost of special nursery care in neonatal intenside care units and special nurseries for premature and other high-risk newborns	55 million
Portion of costs for special child health services attributable to mental retardation from in-born errors of metablism, con-genital rubella, lead poisoning, and related conditions	(undetermined)
Department of Education	
Costs of early intervention programs for children with developmental delays or conditions known to be associated with mental retardation, such as Down's syndrome, fetal alcohol syndrome, or prematurity	19 million

BENEFITS OF PREVENTION PROGRAMS

Investing in prevention programs is a recent effort, but there is evidence that the benefits save enough to be cost effective, even without taking the human costs into account.

Billions Saved by Immunization Program

The most dramatic cost benefit demonstrated to date has been the outcome of vaccination programs. Ten years of immunization against measles have saved the United States $1.3 *billion* by averting 24 million cases, saving 2,400 lives, and averting 7,900 cases of mental retardation (Witte and Axnick 1975).

Cost Savings from Providing Prenatal Care

Advocates estimate that Ohio saves $4 for every $1 invested; the Harvard School of Public Health concluded in 1978 that $1 spent on prenatal care would save $3 in hospitalization; and the Virginia Prenatal Services Advisory Council concluded that Virginia could save $49.8 million in medicaid by providing better prenatal services (Children's Defense Fund 1984).

Cost Savings from Providing Prenatal and Neonatal Testing

Massachusetts estimates that screening for genetic disorders such as trisomy 18, Down's syndrome, Hunter's syndrome, and Tay-Sachs disease will save $2-$20 *per dollar of cost* (Colorado Developmental Disabilities Council 1984).

The Centers for Disease Control, Atlanta, estimate that screening for fetal neural tube defects would cost $2 million to screen 100,000 women; but the total economic benefits would exceed $4 million (Layde, vonAllmen, and Oakley 1979).

Cost Savings from Following Up Infants at High Risk

Savings of $573,500 to California's medicaid program for the first two years of follow-up were reported for a project that cost $557 per infant (Children's Defense Fund 1984).

Cost Savings from the Women, Infant, and Children Nutrition Program (WIC)

A study of births in Massachusetts shows that for every $1 spent on the WIC program that provides food supplements to women and children, $3 in medical expenses were saved (Kennedy, Austin, and Timmer 1983).

HOW NEW JERSEY WILL BENEFIT FROM PREVENTION PROGRAMS

In the following chapter, we review the causes of mental retardation and the numbers of people who are at risk to determine where we should develop programs that can bring New Jersey's citizens substantive benefits.

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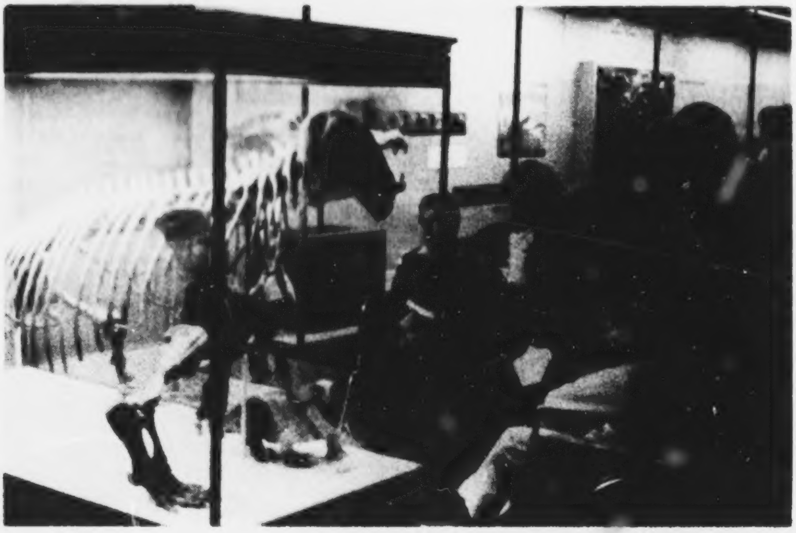

CHAPTER 4

CAUSES OF MENTAL RETARDATION AND PEOPLE WHO ARE AT RISK

Known and suspected causes of mental retardation operate primarily in the early periods of life. First, *before conception and during pregnancy,* the parents' genetic systems and many elements of the organic, physical, and social environments can affect reproduction and the development of the fetus. Second, *at birth,* there are complications of delivery and of the development of the newborn that are known to affect the brain and increase the risk of a severe impairment. Third, *during childhood,* childhood diseases and illnesses, malnutrition, poisoning, abuse, neglect, and accidents may result in mental retardation.

In this chapter, we describe briefly what is known about these causes and the data that we could locate on people in New Jersey, or in the nation, who may be at risk for these conditions. The chapter follows the order of the accompanying list.

KNOWN AND SUSPECTED CAUSES OF MENTAL RETARDATION

1. BEFORE CONCEPTION AND DURING PREGNANCY

A. ORGANIC CONDITIONS

Chromosomal abnormalities
Genetic abnormalities
Congenital infections and maternal diseases

B. ENVIRONMENTAL CONDITIONS

Environmental contaminants
Alcohol
Drugs
Radiation

C. SOCIAL CONDITIONS

Adolescent pregnancy
Prenatal care

2. AT THE TIME OF BIRTH

Preterm births
Birth complications and high-risk conditions

3. DURING CHILDHOOD

Childhood diseases
Malnutrition
Lead poisoning
Child abuse and neglect
Accidents
Poisoning

1. BEFORE CONCEPTION AND DURING PREGNANCY

A. Organic Conditions

CHROMOSOMAL AND GENETIC ABNORMALITIES

The cellular structure of life in its nuclear network contains bodies, called chromosomes, that carry genes. As new cells develop by replication, the nucleus of each has the same number of chromosomes as the parent cells. Almost any alteration in the chromosomal material, even a small addition or deletion, results in significant dysmorphic features, many associated with mental retardation. Some causes of mental retardation can be identified with alterations in the overall structure of the chromosomes; others can be identified with single genes.

CHROMOSOMAL ABNORMALITIES

Down's Syndrome

One of the best documented chromosomal abnormalities is Down's syndrome (Goldberg 1979; Hook and Chambers 1977). Children with Down's syndrome tend to have low muscle tone, slow growth, and mental retardation. Along with these may come serious heart disease, vision problems, low resistance to infection, and intestinal blockages.

This relatively common condition arises from the presence of an extra chromosome 21. The extra material may develop because pairs of chromosomes fail to separate during formation of the sperm or ova, because genetic material may be "translocated" to another chromosome, or because an abnormal separation of chromosomes may occur after conception.

Advanced maternal age appears to be one condition associated with the occurrence of Down's syndrome, although at least one form, the translocation form, appears to recur in families and may therefore not be associated with age itself.

The incidence of Down's syndrome in the general population is usually cited as about 1 in 650 live births, and for women aged 35 years, the incidence is about 1 in 300 live births. The likelihood of Down's syndrome increases twenty-fold at maternal age 45 years (National Association for Retarded Citizens n.d.).

There is evidence that the incidence is decreasing. In the nation, the incidence of Down's syndrome (not all of it associated with advanced maternal age) has decreased: from 1.33 per 1,000 live births in 1960 to 0.99 per 1,000 live births in 1978 (Freeman 1985). The numbers of children born with Down's syndrome have declined because fewer older women are having children (McCormack, Briglia, and Coppola), as shown in Tables 4-1 and 4-2.

Table 4-1. — Percentage age distribution of mothers of persons with Down's syndrome who were placed in institutions, by date of birth, for New Jersey, 1920-1969*

Date of birth	Number in insti-tutions	Mother's age (years)								
		0-19	20-24	25-29	30-34	35-39	40-44	45 +	Age 35 or over	Aver-age
1920-29 . .	90	.08	.12	.10	.21	.17	.29	.67	34.3	
1930-39 . .	132	.02	.11	.06	.22	.23	.17	.19	.59	35.2
1940-49 . .	246	.07	.18	.13	.21	.26	.11	.04	.41	32.2
1950-59 . .	343	.05	.13	.18	.18	.30	.15	.01	.46	33.2
1960-69 . .	165	.073	.16	.17	.15	.25	.17	.02	.45	32.6

SOURCE: McCormack, Briglia, and Coppola 1980

*Data obtained from the New Jersey State Schools: Hunterdon, New Lisbon, Totowa, Vineland, Woodbine, Woodbridge.

Table 4-2. — Percentage age distribution of mothers of all live births, by date of birth of child, for New Jersey, 1920-1969*

Date of birth	Number in insti-tutions	Mother's age (years)							
		0-19	20-24	25-29	30-34	35-39	40-44	45 +	Age 35 or over
1920-29	587,488	.08	.27	.28	.21	.12	037	.003	.16
1930-39	588,927	.09	.29	.29	.19	.10	028	.002	.13
1940-49	842,001	.06	.29	.33	.21	.09	019	.001	.11
1950-59	1,182,401	.07	.28	.32	.21	.10	001	.009	.11
1960-69	1,256,932	.11	.33	.28	.17	.09	019	.001	.11
1970-76	700,866	.13	.31	.34	.15	.05	014	.006	.07

SOURCE: McCormack, Briglia, and Coppola 1980

*U.S. Vital Statistics.

Advanced maternal age and a history of multiple spontaneous abortions are the principal risk factors for Down's syndrome. A person with the syndrome, if fertile, has a 50 percent chance of conceiving a child with the same disorder. Such births are rare, however. Medical interventions (heart surgery), deinstitutionalization, and improved training and education have greatly improved the future of children with Down's syndrome.

Klinefelter's Syndrome

Klinefelter's syndrome in males affects primary and secondary sexual characteristics, and mental retardation has been reported for most cases (Haddad and Wilken 1959). The syndrome occurs in 1 of 450 male births. Some tertiary prevention is possible with estrogen or testosterone therapy.

Fragile-X Syndrome

For many years, mental retardation has appeared to be more common among males. One recently discovered chromosomal anomaly that explains this is fragile-X syndrome. About 1 in 346 live male births displays this syndrome of mental retardation and enlargement of bodily and facial features. Some 80 percent of males who have this genetic defect display mental retardation. Prenatal diagnosis makes prevention possible.

GENETIC ABNORMALITIES

Chromosomes, part of the nucleus of each cell, are composed of thousands of paired genes. Certain genes, certain combinations of genes, as well as damage to the chromosome may cause congenital malformations where ova or sperm cells are affected. More than 3,000 traits and diseases are known to be caused by single genes. There are both inborn errors of metabolism and other genetic diseases.

Inborn Errors of Metabolism

Phenylketonuria. — Phenylketonuria (PKU) *in the untreated child* usually becomes evident in infants about six months after birth. They display a light coloring of the hair and eczema, a "musty" body odor, convulsions, and severe mental retardation. A recessive gene, gotten from both parents, deprives a child of an enzyme needed to metabolize certain common proteins. PKU occurs in about 1 in 10,000 live births.

Early detection and a special diet make it possible for affected children to develop normal intelligence. Routine screening of infants in New Jersey during 1979-1983 has made it possible to detect and prevent mental retardation for 31 cases (New Jersey Department of Health 1984). The diet is, ordinarily, discontinued by the time a child enters school.

A women of childbearing age who has PKU and who is no longer being treated is at high risk of having a severely retarded child. This condition, called *maternal PKU*, is becoming more common. As a result of routine screening and early treatment nowadays, women who have PKU are reaching the childbearing years with IQ's in the normal range. While they do not commonly pass PKU to their children by genetic means (since their spouses are not likely to carry a PKU gene), the infant may be exposed in the womb to high concentrations of the by-product of phenylalanine metabolism in the mother's blood.

There is no known treatment of the children of mothers with phenylketonuria because the children are born with a malformed brain (MacCready, Levy, and Mitchell n.d.), but identifying women who have PKU and encouraging them to resume the special diet before the onset of pregnancy can prevent a mother's PKU from affecting her child.

Galactosemia. — Infants who survive infection owing to this inborn error of metabolism develop cirrhosis, cataracts, and mental retardation. Early detection indicates a simple treatment: total exclusion of milk and milk products from the diet.

Screening for galactosemia in New Jersey identified 3 cases in 1983 (New Jersey Department of Health 1984).

Hypothyroidism. — "Cretinism" is an old fashioned term for the syndrome that arises from hypothroidism in the newborn. A deficiency of the thyroid hormone is associated with lowered basal metabolism, a sallow, puffy appearance, dryness of the skin and hair, anemia, and various conditions described as "apathy," in mild cases. In severe cases, physical and mental growth are stunted, the skin is thick and dry, tongue and abdomen protrude, the stature is dwarfish, and intelligence is very low.

In newborns, hypothroidism used to be diagnosed rarely because signs were not conspicuous so that damage to the central nervous system was not detected until too late. Treatment with thyroid hormone must be initiated as soon as possible after birth. Nowadays, large-scale screening is possible, and New Jersey has been screening newborns for hypothyroidism since 1979. Some 96 cases were detected in New Jersey in this way during the years 1979-1983, or about 1 in 5,000 live births (New Jersey Department of Health 1984).

Homocystinuria. — Mental retardation, abnormalities of the lenses and extremities, and a tendency to thrombosis result from this inborn error of metabolism. Treatment by means of a special diet prevents the development of complications in early infancy. Routine screening in conjuction with screening for phenylketonuria is required in 16 states and voluntary in 2 (United States Department of Health and Human Services 1980).

Maple syrup urine disease. — A very rare metabolic disorder is known for the odor of maple syrup in an infant's urine. Lethargy, weight loss, convulsions, and hypotonia are present, and death occurs by the sixth week. Treatment by means of a complicated infant formula must follow immediately on early diagnosis. Thanks to screening and early treatment, a number of infants with maple syrup urine disease are now normal children.

Tay-Sachs disease. — An enzyme deficiency, found mainly among descendants of Eastern European Jews, is characterized by deposits of substances in various tissues that lead to degeneration of the nervous system, blindness, deafness, severe mental retardation, and death by age 5 years *(Ibid.)*. This condition occurs in 1 of 3,600 live births to Eastern European Jews, and 1 in 30 are carriers of the gene. No treatment is currently available beyond treatment of the symptoms, although prenatal diagnosis is possible, and carriers can be identified prior to marriage.

Lesch-Nyhan syndrome. — About 1 in 50,000 live male births may display Lesch-Nyhan syndrome, with mental retardation, spasticity, and self-mutilation as the most common features *(Ibid.)*. Prenatal diagnosis is possible, and recent advances in genetic engineering may suggest that genetic engineering may be applicable to the disease.

Neurofibromatosis, tuberous sclerosis and Sturge-Weber syndrome. — About 1 in 3,000 live births may display the light brown patches on the skin and tumors on and beneath the skin that are diagnostic for neurofibromatosis. In about 10 percent of these cases, there is mental retardation and there are seizures because of the tumors. Much rarer is tuberous sclerosis (1 in 100,000 live births), in which calcifications in the skull and severe mental retardation appear beginning about the third year. Even rarer is Sturge-Weber syndrome, which includes similar abnormalities in the skin and bone structures, seizures, and mild to severe mental retardation (Vitello and Soskin 1985).

Other Genetic Diseases

Rh hemolytic disease. — In Rh hemolytic disease, antibodies from the Rh-negative mother's blood cross the placenta and destroy the red blood cells of the Rh-positive fetus. In about 15 percent of the white population and 5 percent of the black population, Rh incompatibility triggers the mother's immune system and affects her *second* child in this way.

Damage arises because the red cells lose the capacity to carry oxygen, and this engenders severe anemia and elevated bilirubin (jaundice). Mental retardation, deafness, cerebral palsy, seizures, or death affected an estimated 30,000 infants in the United States in 1978 (Poe 1982).

Since 1968, a vaccine, Rh immune globulin, has made prevention of this disease possible, but the problem remains to get the immune globulin to women who should receive it.

Table 4-3. — Numbers and percentages of newborn screening programs, by program, for 50 states and the District of Columbia, 1980

Condition	Testing program				Expected incidence per year in New Jersey**
	Required		Voluntary		
	Number	Percent	Number	Percent	
Total	...	100.00	...	100.00	100.00
Phenylketonuria*	48	94.11	3	5.88	6-9
Hypothyroidism*	41	80.39	7	13.72	16-20
Galactosemia* ...	23	45.09	5	9.80	0-2
Homocystinuria ..	16	31.37	2	3.92	0.50
Maple syrup urine disease....	16	31.37	3	5.88	0.50
Sickle cell anemia	7	13.72	10	19.60	50.00
Tyrosinemia	6	11.76	2	3.92	na
Tuberous sclerosis	1	1.96	0	0.00	na
Histidinemia/ adenosine deaminase deficiency	1	1.96	0	0.00	3-4

SOURCES: United States Department of Health and Human Services 1980 and New Jersey Department of Health 1984d

*New Jersey law requires screening for this condition.

**Based on 100,000 live births per year.

Neural tube defects. — The neural tube, which is an embryonic structure that runs from the head to the base of the spine, encloses the spinal cord. It may be flawed if the bones of the spine fail to develop around a section of the spinal cord, and this is commonly called spina bifida. Where the brain and skull do not develop (anencephaly), infants do not live much beyond birth; where the spine is "open," 60 percent will die before age 5 years; and where the flaw is closed by skin, 40 percent will die before age 5 years. In recent years, spina bifida has been treated surgically to repair the defective tube with increasing success.

Associated with spina bifida is a condition called hydrocephaly ("water on the brain"). This requires a surgical procedure that shunts fluids so the fluid on the brain can be drained off, to decrease the intracranial pressure.

By no means are all persons with spina bifida mentally retarded. Mental retardation is often associated with spina bifida infants who have hydrocephaly. Survivors sometimes have paralysis of the lower limbs and loss of bowel and bladder control.

Muscular dystrophy. — There is a group of chronic, hereditary diseases that degenerate the muscular tissue. Duchenne muscular dystrophy, one of the types, is associated with mental retardation. This is a sex-linked genetic condition that affects young boys aged 2-6 years, owing to a defective gene from the mother. The mechanism is unknown and there is no treatment.

There are preventive strategies available. Some 90 percent of the girls who are carriers can be detected before they reach age 16 years (Angelini, Armani, and Bresolin 1980). Prenatal diagnosis is possible in the third trimester (Schapira 1980) and routine detection immediately after birth is reliable. Genetic counseling, after the birth of the first boy, could prevent subsequent cases for the same mother; and every sister of an afflicted boy is at high risk of having affected children. As to secondary prevention, early detection can mean early physical therapy and preparation of parents for living with a handicapped child (Scheuerbrandt 1980)

SCREENING FOR CHROMOSOMAL AND GENETIC ABNORMALITIES

Perhaps as much as one-fourth to one-third of mental retardation is owing to chromosomal and genetic causes. New Jersey collects data on chromosomal and genetic conditions by means of screening programs that are required by state laws and regulations. Pregnant women can be screened, newborns can be screened, and carriers (family members) can be screened. Screening does not automatically prevent anything, unless treatment is possible. For this reason, New Jersey chooses to screen for those causes *for which some treatment is possible*, although other states screen for more causes.

A summary of where New Jersey stands in the national picture of screening for genetic and chromosomal conditions of mental retardation is shown in Table 4-3.

Screening Pregnant Women

In 1983, the New Jersey Department of Health counseled 440 families for chromosomal abnormalities, as shown in Table 4-4.

Table 4-4. — Numbers of chromosomal abnormalities for families counseled and persons tested, for New Jersey, 1983

Chromosomal abnormality	Families counseled	Total tested	Chromosomal abnormality found in:	
			Parent	Child
Total	**440**	**420**	**98**	**373**
Down's syndrome	135	98	1	194
Other chromosomal defect	147	73	49	173
Fetal death	32	16	1	3
Reproductive failure	126	233	47	3

SOURCE: New Jersey Department of Health

Amniocentesis is about the only preventive strategy for many causes of mental retardation so far. In 1983, amniocenteses detected chromosomal and other defects shown in Table 4-5.

Screening Newborns

New Jersey screens all newborns for phenylketonuria (PKU), galactosemia, and congenital hypothyroidism. In 1983, among 98,746 live births, 6 cases of phenylketonuria, 3 cases of galactosemia, and 23 cases of hypothyroidism were found. (These data are tabulated in Table 7-5 of our recommendation, "Expand Genetic and Teratologic Counseling.")

Table 4-5. — Amniocentesis and abnormalities detected, for New Jersey, 1983

Amniocentesis and abnormalities	Number
Amniocenteses	3,275
Abnormalities detected	
Chromosome	110
Neural tube defects	7
Biochemical defects	4
Other	5

SOURCE: New Jersey Department of Health

Screening Families

New Jersey screens at-risk individuals for genetic traits as part of routine health and pregnancy management. Recessive conditions for which there is a test are sought by "genetic carrier screening programs" for which a population to be tested can be defined. Although a number of genetic conditions are screened for, Tay-Sachs disease, which affects persons of Eastern European Jewish descent, is the only one associated with mental retardation. In 1983, 842 persons were tested for Tay-Sachs disorder with 31 people identified as carriers and none identified as having the disease (New Jersey Department of Health 1985c).

One mechanism for identifying families at risk for the occurrence of mental retardation is to provide genetic counseling for families with a previously affected mentally retarded child. New Jersey provided genetic counseling services to 216 families for the purpose of counseling for mental retardation. This probably represents only a small fraction of the families appropriate for such a service *(Ibid.)*.

CONGENITAL INFECTIONS AND MATERNAL DISEASES

Congenital Infections

Many infections have a devastating effect on the developing fetus, even when effects on the health of the mother may be minimal. One of the devastating effects of a congenital infection may be mental retardation. Infections such as rubella, cytomegalovirus, and several venereal diseases are example of infections that can produce severe mental retardation in the newborn.

Cytomegalovirus and toxoplasmosis. — Cytomegalovirus is an intrauterine or early postnatal infection that damages the central nervous system and causes mental retardation. Toxoplasmosis is a disease caused by a parasitic microscopic protozoan that can be contracted from improperly cooked meat or from animal feces. It damages the central nervous system and produces hydrocephaly, microcephaly, mental retardation, eye defects, and seizures (Illinois Bureau of the Budget 1979).

It appears that as many as 1 percent of all pregnancies are infected with cytomegalovirus, but not all result in severe mental retardation in the child. Toxoplasmosis is reported to occur in 0.2-0.5 percent of gestations. Fetal transmission is reported at 15 percent in the first trimester, 25 percent in the second trimester, and 60-65 percent in the third trimester (Burkett 1983).

Rubella. — The earlier rubella is contracted by a pregnant woman, the greater the risk. Contracting rubella during pregnancy, especially during the first four months, may result in multiple handicaps, including cataracts, deafness, heart defects, cerebral palsy, encephalitis, or microcephaly.

Epidemics of rubella came in waves every 6-8 years, until vaccines were licensed in 1969. Following the rubella epidemic of 1964 in the United States, there were 20,000 cases of congenital rubella (Witte and Axnick 1975); 1,800 cases of mental retardation; 12,000 cases of deafness or deaf-blindness; 6,300 miscarriages; and about 2,200 deaths (Poe 1982).

Is another epidemic possible? The epidemic of 1964 was the last major epidemic for the United States, because vaccination programs for children aged 15 months have reduced cases to fewer than 10 in 1984. However, a residual of unprotected women is entering childbearing in this decade because they neither have had the disease nor been vaccinated.

For the United States, 10-15 percent of pregnant women were estimated to be susceptible by Burkett (1983), and Ziskin and Finley (1980) estimated in 1980 that 22-100 infants might be born with rubella syndrome. Aggressive immunization programs have reduced dramatically the numbers of infants born in the United States with rubella syndrome: from 20,000 (1964-1965) to 20 (1983). Kern (1984) reports that during 1979-1982, 8 children registered with the New Jersey Department of Health with the diagnosis of congenital rubella at ages up to 15 years as of 1983.

Sexually-transmitted diseases. — Venereal diseases include syphilis, gonorrhea, and herpes. Mental retardation is frequent in untreated congenital syphilis. Untreated gonorrhea causes blindness in the newborn; and congenital herpes is associated with inflammation of the eye, an abnormally small head, and circulatory disorders. Gonorrhea and syphilis have increased during the past ten years, especially among teenagers of all socioeconomic classes (National Association for Retarded Citizens, n.d.)

For the United States in 1983, 32,698 cases of primary and secondary syphilis were reported. For New Jersey in 1983, 815 cases of primary and secondary *syphilis* were reported, up from 658 cases in 1982 (Miller *et al.* 1984).

In the United States, herpes simplex virus causes brain damage and retardation in about 125 infants born to 1,000 women with active HSV-2.

Maternal Diseases

Maternal diabetes. — Diabetes mellitus is a chronic disease caused by lack of insulin that affects how the body uses glucose. The effect of maternal diabetes on the fetus is either excessive or retarded growth that may be associated with congenital malformations.

Growth may be either excessive or retarded because there are two forms of maternal diabetes. The first may not be detected until laboratory tests are carried out during pregnancy. The second may be of long duration.

Excessive growth makes delivery more difficult and premature birth and cesarean section more likely. The infant may be damaged during the birth process because of its size. These infants often display heart- and skeletal defects, respiratory distress, jaundice, hypoglycemia, neurologic problems, and convulsions.

Retarded growth affects birth weight, may result in underdevelopment of the brain, and is often accompanied by vision problems, toxemia, high blood pressure, and swelling of the limbs in the mother (Poe 1982).

Toxemia and other maternal disorders. — *Toxemia* is a disease of unknown origin that affects the brain, heart, kidney, and liver, among other organs and that can be diagnosed only after the twentieth week of gestation. *Heart disease* in the mother may affect the circulation of blood to the fetus and retard all aspects of growth. *Renal disease*, disease of the urinary tract, may occur with toxemia and may have adverse effects on the fetus. *Blood diseases* include the anemias, which reduce the delivery of oxygen to the developing fetus.

B. Environmental Conditions

CONTAMINANTS

Chemicals, gases, and radiation are among the substances that can affect the reproductive cells or the fetus. Substances that affect the developing fetus are called "teratogens"; while substances that affect the reproductive cells are called "mutagens." The fetus and the reproductive cells can be affected through many channels, including tobacco and alcohol; common household chemicals, industrial chemicals in the workplace; and substances used in medicine (President's Committee on Mental Retardation 1980).

WE NEED TO LEARN MORE ABOUT CONTAMINANTS

The discovery of how mutagens and teratogens work is gradually making everyone more sensitive to "the environment" (Hall and Klotz 1985).

People are exposed to a wide variety of chemical contaminants in community and occupational settings. At *high* concentrations, some of them are known to cause mental retardation, learning disabilities, or behavioral disorders. Much research remains to be done on these risks, for at least four reasons.

> First, the effects of a biologically active substance may vary in different animal *species*. Most of our data on environmental contamination come from studies of non-human species.
>
> Second, the type and magnitude of the effects may also depend on the *stage of development* at which exposure occurs. The period when organs are developing is the most sensitive stage to gross structural changes including neurological ones. Current understanding of embryonic and fetal brain development indicates that the highest risk of mental retardation occurs when exposure occurs between 8 and 16 weeks of gestation. Permanent developmental damage can also occur in the newborn following postpartum exposure via lactation and in early childhood. Yet brain development continues throughout life. Thus, the adverse effects of an exposure may not show up until adulthood.
>
> Third, the exposure *dose* is another important determinant of effect. While exposure to a low level of lead may produce subclinical or subtle neurological changes, exposure to a high level may manifest itself as severe clinical disease, including encephalopathy.

Fourth, the ultimate sources of environmental contamination are a *complex network*. For example, the New Jersey Department of Environmental Protection and the United States Geological Survey have begun an investigation to determine if lead contamination of groundwater in New Jersey is related to "acid rain" (Tucker 1985).

NEW JERSEY HAS AND NEEDS AN AGRESSIVE PROGRAM ON THE ENVIRONMENT

New Jersey, of all the states, has probably the most vigorous programs of enforcement of environmental laws to combat toxic and hazardous chemical contamination, and is nationally recognized for its efforts to identify and deal with these problems. Over the past decade, it became more and more apparent that our state faced extremely serious problems with chemical wastes and environmental pollution. A statewide study of toxic chemicals in groundwater aquifiers, begun in 1977, showed low-level but fairly widespread contamination in wells throughout New Jersey (Tucker 1981). New Jersey has more sites on the "Superfund" National Priority List than any other state; these are sites which pose substantial environmental and public health problems.

New Jersey's efforts to combat the problems of chemical contamination came from necessity; our dense concentration of chemical industries, with many plants older than the turn of the century, has left a legacy of problems. Moreover, many years of illegal and irresponsible disposal of toxic wastes have left their mark.

Thus, continued vigorous enforcement of national and state laws to prevent pollution and to clean up past contamination must be maintained. Research to find better ways to deal with chemical waste is imperative. Much still needs to be done to ensure that New Jersey residents have minimized exposure to substances that are suspected of contributing to increased risks of cancer, of birth defects, or of other negative health outcomes.

Teratogens may be more important causes of mental retardation than we now suspect. Our data on all developmental defects in humans suggest that about 20 percent arise from genetic conditions, 5 percent from chromosomal defects, and 10 percent from known environmental agents. This means that at least 65 percent of human developmental defects, then, arise from *unknown* causes (Paull and McCormack 1980). But clinical models that use X-ray irradiation, common drugs (dilantin, aminopterin, and coumadim), and ethyl alcohol, suggest that a much larger percentage of developmental disabilities may very well be owing to the teratogenic effects of even common household agents (McCormack 1981).

More data on how teratogens affect conception and gestation have to be developed. New Jersey has had a limited teratology services program since 1982. This program counsels physicians and patients, upon inquiry, about teratogens. Located in the School of Osteopathic Medicine of the University of Medicine and Dentistry of New Jersey, the program has been the primary source of information on teratogens. About 1,300 consultations were provided in the first two years of the program, and, as time goes on, this program should develop extensive data on teratogens for New Jersey and for the nation.

ALCOHOL

Alcohol is a chemical that is routinely consumed in our society. While there are no findings yet to support the statement that even small amounts of alcohol have effects on the fetus, heavy drinking increases the risk that a newborn will have poor muscle tone and sucking response, mental retardation, stillbirth, and spontaneous abortion; and moderate drinking increases the risk of low birthweight, decreased bodily activity and tremors, poor sucking response, and suppressed fetal breathing. Binge drinking has been associated with brain malformations.

Many professionals identify a "fetal alcohol syndrome," a combination of central nervous system disorders; growth deficiencies; facial anomalies; and skeletal, urogenital, and cardiac disorders. Professionals refer to partial expressions of these clinical features as "fetal alcohol effects," where the damage to the fetus may be more subtle. Infants with fetal alcohol syndrome are almost always mentally retarded.

ALCOHOL USERS

The New Jersey Department of Health (1985b) reports that in New Jersey, 132,497 women are estimated to have alcohol problems. As many as 190 infants may be born each year with full fetal alcohol syndrome and more than 400 may be born with fetal alcohol effects.

In 1983, only 5,690 women were admitted to treatment programs (New Jersey Department of Health 1985b). This probably means that many alcoholic fertile or pregnant women are unidentified and untreated. The outcome of this may be that there are many more cases of fetal alcohol syndrome or the effects than are reported.

DRUGS

Many drugs are known to affect the central nervous system adversely in humans (Melnick 1980) and animals, and the effects vary widely. These may be illegal, prescribed, over-the-counter, or social drugs.

The most serious consequences arise when drugs are used by pregnant women. Some consequences, in addition to mental retardation, are overmasculinization; withdrawal symptoms; depressed motor, heart, and respiratory rates; central nervous system reactions; impairments of sucking and feeding; fever, irritability, and lethargy; severe hyperbilirubinemia; fetal abnormalities; chromosomal defects; and high abortion rates (Ferguson, Lennox, and Lettieri 1974). Table 4-6 lists just a few drugs and their documented effects.

Table 4-6. — Some examples of drugs and their effects on humans

Drug	Effect
HUMANS	
Alcohol	Malformations of the brain and skull; disorganization of the brain, hindbrain, and brainstem and displacement of the spinal matter; mental and motor retardation
Anticonvulsants	Malformation of the skull; mental retardation
Aminopterin	Malformations of the brain and skull; underdevelopment or fusion of the cranial sutures
Methotrexate	Malformations of the skull; absence of the cranial sutures
Thalidomide	Hydrocephaly; cranial nerve dysfunction, deformations of the limbs
Tubocurarine	Multiple abnormalities of the limbs, including permanent flexure of the joints

SOURCE: Melnick 1980; Joffe 1979

Addiction in an infant is a serious matter. Restlessness, hyperactivity, and convulsions suggest central-nervous-system damage; lack of appetite, vomiting, diarrhea, and progressive debilitation are common. Coma, shock, respiratory distress, and electrolyte imbalance and a high rate of mortality may accompany withdrawal from drugs in newborns *(Ibid.)*.

There are difficulties in designing a program to prevent damage to the fetus from drugs and medications:

> These agents often have their adverse effects when the mother and the professional are least likely to be aware of them. Very different effects can come from the same drug, depending on dose, on when it is taken, and on the organs and tissues that are concerned.
>
> It is in the earliest period of gestation, when a woman may not be aware she is pregnant, that these may have there most adverse effects. Thalidomide and dilantin are well-known examples (Poe 1982).
>
> It is especially difficult to detect and prevent the effects of narcotics. Users of intravenous drugs may avoid prenatal care to escape detection. Their infants risk addiction (estimated at 80-90 percent) before and after birth and they risk obstetrical complications, including toxemia, breach birth, premature birth, hepatitis, blood clots, and tetanus.
>
> A recent study conducted under a grant from the National Institute on Drug Abuse found that nearly one-half of all heroin addicts are alcoholics or have drinking patterns pointing to alcoholism.
>
> The prevalance of those who abuse soft drugs is difficult to assess. Those who abuse soft drugs often are unaware of their addiction. Drugs frequently are prescribed, sometimes by a number of physicians, and potential problems are not identified. These drug abusers often may develop psychological or physical symptoms that require them to enter the health system or mental health system but their addiction may not be identified.

Smokers

Smoking is a form of drug use that is casually accepted as sociable, yet that is associated with low birth weight, especially during the second half of pregnancy. Mothers who smoke while pregnant tend to have babies that weigh an average of seven ounces less than babies of mothers who do not smoke. Studies suggest, too, that perinatal mortality increases directly with the level of maternal smoking during pregnancy.

Data collected through the New Jersey State Special Supplemental Food Program for Women, Infants, and Children (WIC), presented in Table 4-7, show that among pregnant women of all ages, a greater percentage of smokers (8.8 percent) than non-smokers (5.5 percent) had low-birth-weight babies (weighing less than 2,501 grams).

Table 4-7. — Percentage of infants born at various birth weights bv age of mother and her smoking on initial visit to the State Special Supplemental Food Program for Women, Infants and Children (WIC) for 3,826 pregnant women, in New Jersey, 1982

Mother's Age	Number	Percentage of infants born at these birth weights (grams)			
	Total	Total	Less than 2,501	2,501-3,900	Greater than 3,900
All Ages					
Smokers	1,120	100.0	8.8	86.5	4.7
Non-smokers	2,706	100.0	5.5	84.6	9.9
Younger than 15 years					
Smokers	5	100.0	0.0	100.0	0.0
Non-smokers	29	100.0	13.8	86.2	0.0
15 - 19 years					
Smokers	317	100.0	8.5	89.0	2.5
Non-smokers	764	100.0	7.3	87.2	5.5
20 - 34 years					
Smokers	767	100.0	9.0	85.1	5.9
Non-smokers	1,791	100.0	4.6	83.8	11.6
35 - 49 years					
Smokers	31	100.0	6.5	93.5	0.0
Non-smokers	122	100.0	4.9	79.5	15.6

SOURCE: New Jersey Department of Health 1984b

Retardation in fetal growth could be a direct effect of the toxic substances in tobacco smoke or an indirect effect of the restriction smoking puts on the mother's gaining weight or supplying oxygen and nutrients through the placenta (Sherman 1984).

Data collected for New Jersey show that for the year 1982, 30 percent of females and 35 percent of males could be considered smokers. Table 4-8 compares data for females and males in New Jersey and the nation. In the younger age cohorts (18-34 years), fewer females in New Jersey smoke.

Table 4-8. — Percentage of the population who currently are smokers by sex and age, for New Jersey and the United States, 1982

Age (years)	Percentage of the population who currently are smokers			
	Females		Males	
	New Jersey	United States	New Jersey	United States
All ages 18 years and over	**29.7**	(a)	**35.2**	(a)
All ages 20 years and over	(a)	**29.4**	(a)	**38.3**
18-24	23.1	0	1.4	0
20-24	0	32.7	0	39.7
25-34	27.6	31.6	41.1	43.1
35-44	35.5	34.9	32.6	42.6
45-65	38.6	30.8	33.9	40.8
65 and over	16.0	16.8	19.6	17.9

SOURCE: Miller *et al.* 1984

(a) New Jersey reports for all ages over 18 years; the United States reports for all ages over 20 years.

A survey (Table 4-9) of New Jersey high school students (grades 10-12) suggests that cigarette use among this age group remained stable during the years 1980 to 1983.

Table 4-10 gives some indication of the age at which students say they begin their use of various substances. Before reaching the 10th grade in school, 82 percent had used alcohol, 41 percent had used marijuana, and 20 percent had used amphetamines.

"Hard Drugs"

Considerable statistical analysis has been done by the state to determine the prevalence of heroin use. Some examples are shown in Table 4-11. The

Table 4-9. — Percentages of high-school students who reported using cigarettes, by current use of cigarettes, for New Jersey, 1983 and 1980

Current use of cigarettes	Year	
	1983	1980
Total	**100.0**	**100.0**
Never	58.5	60.4
On occasion	20.5	18.9
One-half pack or less per day	9.4	9.8
One-half to one pack per day	9.7	9.2
More than one pack per day	1.9	1.7

SOURCE: Fisher 1984

results of this analysis indicate that there are about 42,000 abusers in the state; 33 percent of them in Essex County.

Essex County has the highest rate in the state and the rate exceeds that of the highest standard metropolital statistical area in the nation. Essex County presents the highest indicators of mortality, morbidity, and admission to treatment in a recent survey (New Jersey Departments of Health and of Human Services n.d.). Essex rates for overdose deaths, admissions, and arrests were more than twice as high as Union County. Morris County ranked third in the region. People aged 15-35 accounted for the largest number of deaths owing to substance abuse, approximately 74 percent. Those aged 21-24 were the largest single age category.

A major problem of substance abuse exists among youth throughout the state. Table 4-12 suggests the extent to which New Jersey high school students (grades 10-12) use alcohol and drugs. Fisher (1984) surveyed students on their substance use. At the time of the survey, 66 percent had used alcohol during the past month, 29 percent had used marijuana, 12 percent had used amphetamines, and 8 percent had used cocaine.

The statements of these students do not necessarily indicate the extent of a problem in the population. Statewide, drug treatment admissions have increased every year since 1978, after declining in 1977 and 1978: 1976 (18,409); 1977 (13,679); 1978 (10,539); 1979 (17,057); 1980 (21,403). Heroin addiction accounts for 70 to 80 percent of admissions each year.

Table 4-10. — First use of eight substances, by grade in school, for high-school students, New Jersey, 1983

	Percentage				
			Grade in which use began		
	Ever used	Total using before 10th grade	Before 7th	7th-8th	9th
Alcohol	91.8	81.9	34.3	30.6	17.0
Marijuana	56.6	41.1	6.6	18.6	15.9
Amphetamines ..	33.6	20.1	1.9	7.3	10.9
Cocaine	17.8	7.5	1.0	2.1	4.4
Hallucinogens ...	14.6	8.7	1.0	2.9	4.8
Barbituates	12.4	7.8	0.9	3.4	3.5
Tranquilizers	10.9	6.9	1.0	3.0	2.9
Heroin	2.4	1.9	0.6	0.4	0.9

SOURCE: Fisher 1984

Table 4-11. — Estimates of prevalence of use of heroin, selected counties, New Jersey

County	1976	
	Rate per 100 thousand population	Number
New Jersey total	**568.5**	**42,246**
Essex	1,477.4	13,664
Morris	180.4	734
Sussex	82.4 3	72
Union	505.2 3	2,781
Warren	124.3 3	86
Total for this Human Services Area region	847.5	17,347

SOURCE: New Jersey Departments of Health and of Human Services n.d.

Table 4-12. — Exposure of students to drugs and recency of use, by type of drug, for New Jersey, 1983

Substance	Percentage			
	Ever used	Used in past month	Used in past year, but not past month	Used, but not in past year
Alcohol	91.8	65.9	21.0	4.9
Marijuana	56.6	28.9	18.3	9.4
Amphetamines ..	33.6	12.4	11.2	10.0
Cocaine	17.8	7.5	7.2	3.1
Hallucinogens ...	14.6	5.0	5.4	4.2
Barbituates	12.4	4.4	3.0	5.0
Tranquilizers	10.9	3.0	3.2	4.7
Heroin	2.4	1.1	0.2	1.1
Glue	13.4	...	...	...
Cough medicine	4.5	...	...	...
Aerosol.........	4.0	...	...	...
Methadone	3.9	...	...	...

SOURCE: Fisher 1984

Radiation

Ionizing radiation can break molecular bonds and protein and swamp the ability of the body to repair itself. Sources of risk could include power plants, industrial facilities, waste-disposal sites, and diagnostic or other technical equipment (Crawford and Leggett 1980).

Radiation may affect the unborn, the newborn, or adults and their descendants. All organ systems are at risk of malformation and maldevelopment during the gestational period in particular. This is because all the information for the development of the organ systems resides in one cell, the fertilized ovum, and any injury at this stage would be passed on to every cell of the developing organism (Gofman 1981).

Ionizing radiation has been established as a cause of mental retardation from both animal and human studies. Doses of radiation on humans, such as those received by survivors of atomic explosions, damage the central nervous system and continue to be studied very closely because so little is known about what constitutes a harmful dose.

Evaluation of the data on radiation-related mental retardation among those exposed in the womb in Hiroshima and Nagasaki has related fetal damage to the estimated absorbed dose in fetal tissues. Within the critical period of exposure (8-15 weeks), damage, expressed as the frequency of subsequent mental retardation, appears to be directly related to the dose received by the fetus. The data are consistent with a probability of occurrence of mental retardation of 40 percent per 100 rads (Schull 1984). Severe retardation was much higher among the children of Japanese women who were exposed in this way (Wood, Johnson, and Omori 1967; Blot and Miller 1973).

In addition to directly acting on the developing fetus, radiation has been reported to cause mental retardation through genetic damage. Ionizing radiation produces gene mutations and chromosomal aberrations that, if present in the germ cells, may be responsible for the production of abnormal offspring. A chromosomal aberration is responsible for Down's syndrome. Low doses of maternal irradiation, including diagnostic X-rays taken prior to conception, have been reported to be associated with increased incidence of Down's syndrome (Alberman *et al* 1972).

The possibility that low doses of radiation cause mental retardation has been studied little (Brent 1980), but data indicate that the possibility cannot be dismissed (Gofman 1981).

The New Jersey Department of Environmental Protection reported to the council that the Committee on the Biological Effects of Ionizing Radiation (1980)

> ...analyzed a variety of data associated with in utero exposure. They noted that the incidence of microcephaly was 11 percent...for less than 10 rads dose, 17 percent...for 30-49 rads, 70 percent for 50-99 rads, and 100 percent...for doses over 100 rads. In the control group, the incidence was 4 percent. Profound mental retardation was not observed below 25 rads dose (Nicholls 1984).

This information raises the important question for public health: does a dose of radiation have a threshold effect; that is, is there a level below which radiation is harmless? The answer to this is not yet known. As the Department of Environmental Protection reported:

> Doses of 25 rads or greater are rarely encountered outside of radiation therapy or accidents. Doses of 5 rads can occur in diagnostic nuclear medicine procedures. Certain diagnostic radiology procedures can produce doses in the neighborhood of 1-5 rads. Is the risk of 5 rads linearly proportional to the risk at 100 rads? As yet, there does

> not seem to be an answer to this question, and, in view of the very small numbers of cases, [the question] seems likely to remain unanswered for the foreseeable future. In view of the uncertain nature of the data, it would seem prudent to err, if at all, on the side of caution *(Ibid.)*.

For this reason, New Jersey carefully regulates the use of diagnostic equipment through its Department of Environmental Protection.

EXPOSURE TO RADIATION

From 1982-1984, 60 pregnant women were counseled in New Jersey regarding exposure to radiation and isotopes (McCormack 1984). Included are diagnostic, therapeutic, and occupational exposures of radiation to pregnant women.

C. Social Conditions

All organic and environmental causes operate more severely on people who have insufficient resources. Under these conditions that we call "poverty," education and preventive health care are some of the most difficult resources to get. Where people do not have sufficient education and health care, two common outcomes are adolescent pregnancy and inadequate prenatal care.

ADOLESCENT PREGNANCY

Adolescent pregnancy is a problem of wide scope. One of every ten girls will experience at least one pregnancy before age 18 years. In the nation, approximately 1.1 million young women under age 19 get pregnant each year and 600,000 give birth (Alan Guttmacher Institute 1981). For New Jersey in 1983, there were 7,170 births to young women aged 18 and under, with 859 births to girls 15 and under. Resident births, by age of mother and county of residence, are shown in Table 4-13.

Young maternal age puts women at increased risk of complications in pregnancy (bleeding, anemia, prolonged labor, need for cesarian section, toxemia, sexually transmitted diseases, and cervical cancer [Alan Guttmacher Institute 1981]). What is more, their young age puts their infants at increased risk for premature birth, low birthweight, neonatal mortality, and neurological deficits (McCormick, Shapiro, and Starfield 1984). Many children born without neurological abnormality may, nevertheless, suffer sociocultural deprivation with secondary retardation.

Table 4-13. — Resident births, by age of mother and residence, for New Jersey, 1983

Residence	Age (years)						
	Total	15 or less	16	17	18	19 or more	Percent
Total	**98,746**	**859**	**1,275**	**2,112**	**2,924**	**91,576**	**9.4**
Atlantic	2,912	46	53	97	135	2,581	1.8
Bergen	8,743	14	28	43	85	8,573	0.2
Burlington	4,736	24	46	83	146	4,437	0.5
Camden	7,594	101	124	222	295	6,852	1.5
Cape May	1,191	5	18	26	30	1,112	0.4
Cumberland ..	2,059	44	53	100	113	1,749	2.5
Essex	11,829	205	328	429	536	10,331	2.0
Gloucester	3,008	17	27	60	94	2,810	0.6
Hudson	8,276	83	113	225	270	7,585	1.1
Hunterdon....	1,110	2	6	6	12	1,084	0.2
Mercer	4,239	69	72	124	163	3,811	1.8
Middlesex	7,636	30	58	117	167	7,264	0.4
Monmouth ...	6,319	33	58	110	133	5,985	0.5
Morris	4,894	7	14	21	53	4,799	0.1
Ocean........	4,688	29	39	68	128	4,424	0.7
Passaic.......	6,542	95	115	165	249	5,918	1.6
Salem	949	10	9	33	41	856	1.1
Somerset	2,448	3	15	22	39	2,369	0.1
Sussex	1,720	1	10	17	23	1,669	0.0
Union........	6,093	38	78	119	169	5,689	0.7
Warren.......	1,124	2	9	17	29	1,067	0.2
State institutions	9	0	0	0	0	9	0.0
Military	627	1	2	8	14	602	0.2

SOURCE: New Jersey Department of Health 1984

Teenagers get pregnant owing to lack of education and lack of social and emotional supports. Poverty aggravates the normal strong feelings and need for self-expression that adolescents and teenagers experience. The sexual activity that is one consequence of this often results in pregnancy.

For lack of educational resources, about 50 percent never use contraception or use it rarely. For need of emotional support, about 50 percent choose to carry their pregnancy to term (Brookman 1983). For lack of education or social support they often do not seek prenatal care because they are not aware of the symptoms of pregnancy; they are embarassed and secretive; and they are fearful of responsible adults and are ignorant of the health-care systems *(Ibid.)*.

Table 4-14. — Percentages of mothers who received "inadequate prenatal care," by race, for selected states, 1981 (a)

1981	Inadequate prenatal care (percentage)(a)		
	Total	**White**	**Black**
Delaware (e)	4.3	3.8	7.0
Michigan (b)	5.8	4.4	12.6
Detroit (b)	12.1	7.6	13.9
Mississippi	4.5	2.7	6.4
Ohio	3.4	2.8	6.6
Cleveland	4.0	...	...
New York City (c)	18.0	...	...
Bronx	25.2	...	...
Central			
Harlem	33.8	...	...
Tremont	28.7	...	...
Bedford	25.9	...	...
Kansas (c)	4.8	...	...
Kansas City	7.1	...	...
Colorado (c)	4.5	...	...
Denver	6.5	...	...
Oregon (e)	6.4	...	...

SOURCE: Food Research Action Center 1984

(a) "Indequate prenatal care" means care that does not begin until the third trimester and pregnancies in which there is no prenatal care.
(b) Michigan and Detroit report 0-5 prenatal visits as "inadequate care."
(c) New York, Kansas, and Colordo do not report data by race.
(d) Oregon reports 0-4 prenatal visits as "inadequate care."
(e) Delaware, Michigan, Mississippi, and Ohio report "non-white" or "predominantly black populations."

INADEQUATE PRENATAL CARE

So, inadequate prenatal care is more common among low-income women at the younger ages. For example, data collected from vital statistics registries in eight states for the year of severe economic crisis, 1981, reported prenatal visits documented on birth certificates. Inadequate prenatal care is more common among minority women, ranging 26-34 percent in New York's poorest neighborhoods, as shown in Table 4-14 (Food Research Action Center 1984).

Inadequate prenatal care increases the risk that an infant will be born under normal weight. Low birth weight does not cause premature birth, but is the greatest single hazard to an infant. A baby who weighs less than 2,500 grams (5.5 pounds) at birth is more likely to be mentally retarded, have birth defects, and experience other growth problems.

Typically, prenatal care is "inadequate" if there is none or if it does not begin until the third trimester. Under these circumstances, mothers may not control their activities, including their diet and medication.

The infant mortality rates in areas where prenatal care is inadequate are more than twice the national average. The Food Research Action Center

Table 4-15. — Number of live births, by percentages for prenatal care, for New Jersey, 1980 - 1983

Live births and prenatal care Number of live births trimester during which mothers began prenatal care:	Numbered Year			
	1980	1981	1982	1983
Total	**96.410**	**96.127**	**98.225**	**98.746**
First	77.21	77.62	77.86 3	78.53*
Second	15.48	15.14	15.07	14.60
Third	3.39	3.45	3.45	3.22
No care	1.44	1.15	0.74	0.82
Unknown	2.49	2.64	2.88	2.83

SOURCE: New Jersey Department of Health 1984a

* 84.0 percent had adequate care

Table 4-16. — Percentage and trimester in which prenatal care began, by race and age, for resident live births, New Jersey, 1981

Race and age (years)	Percentage and trimester in which prenatal care began			
	Total(a)	First	Second	Third
White				
Under 15	91	43	41	7
15 - 19	100	53	37	10
20 - 24	99	78	17	4
25 - 29	100	90	8	2
30 - 34	99	90	8	1
35 - 39	98	87	10	1
40 - 44	100	82	16	3
45 or older	91	79	12	0
Unknown (b)	100	80	20	0
Black				
Under 15	88	30	41	17
15 - 19	91	46	36	9
20 - 24	93	61	25	7
25 - 29	94	72	18	8
30 - 34	96	76	17	3
35 - 39	94	69	20	5
40 - 44	95	62	30	3
45 or older	100	25	50	0
Unknown (b)	100	50	50	0
Other				
Under 15	0	0	0	0
15 - 19	100	64	21	12
20 - 24	94	67	23	6
25 - 29	98	80	14	4
30 - 34	98	84	12	2
35 - 39	99	81	14	4
40 - 44	100	77	19	4
45 or older	100	100	0	0
Unknown (b)	0	0	0	0

Table 4-16. — Continued.

Race and age (years)	Percentage and trimester in which prenatal care began			
	Total(a)	First	Second	Third
Unknown				
Less than 15	100	0	100	0
15 - 19	16	4	8	0
20 - 24	12	11	1	0
25 - 29	9	9	0	0
30 - 34	6	5	1	0
35 - 39	8	7	1	0
40 - 44	6	6	0	0
45 or older	0	0	0	0
Unknown (b)	0	0	0	0

SOURCE: New Jersey Department of Health 1983

(a) Totals do not sum to 100 percent because data are not complete for all births

(b) History of prenatal care was unknown for 2,537 cases

reports that inadequate prenatal care arises in part from unemployment, which decreases family income for the purchase of private health care. They write that clients who have not paid substantial deposits to hospitals and physicians before going into labor have been turned away and that hospitals have reduced low-profit services such as prenatal care *(Ibid.)*.

IN NEW JERSEY

Overall, most live births follow on prenatal care of some kind in New Jersey. This is becoming more common, as Table 4-15 shows.

Young nonwhite mothers will delay prenatal care until the second trimester, as shown in Table 4-16.

Given proper prenatal care, pregnancies in adolescence do not differ from the population of older women (Zuckerman *et al.*, 1984). However, the younger the mother, the higher that chance for mental retardation in her child.

2. AT THE TIME OF BIRTH

PRETERM BIRTHS

Premature birth and low birth weight are interrelated issues. While prematurity does not *cause* low birth weight. about two-thirds of low-birth-weight infants are born premature. The remaining one-third are born at full term but are "small for gestational age."

Infants who are low in weight, and very-low-birth-weight infants especially, have a high risk of severe impairment: mental retardation, cardiac malformation, congenital cataracts, and cystic fibrosis (Nelson and Broman 1977; Commey and Fitzhardinge 1979; Shapiro *et al.* 1980).

Mortality is far higher among children who are born at a low weight and this is especially true of low-income persons. Black infants are about twice as likely as whites to have low birth weight (Children's Defense Fund 1984). The problem is compounded by the numbers of births to adolescents, who accounted for about 11 percent of births in New Jersey during the years 1979-1981, but who accounted for about 17 percent of the infants who died before their first birthday (Associated Press 1984).

IN NEW JERSEY

Thousands of infants are born each year at low weight or as otherwise small for their gestational age, as shown in Table 4-17.

Table 4-17. — Numbers and percentages of resident live births which were very low birth weight (1,500 grams) or low birth weight (2,500 grams), for New Jersey, 1979-1983

		Live Births			
		Less than or equal 1,500 grams		Less than or equal 2,500 grams	
Year	Total	Number	Percent	Number	Percent
1979	95,661	1,176	1.23	6,854	7.16
1980	96,410	1,147	1.19	6,884	7.14
1981	96,127	1,148	1.19	6,745	7.02
1982	98,225	1,163	1.18	6,700	6.82
1983	98,746	1,205	1.22	6,975	7.06

SOURCE: New Jersey Department of Health 1984a

Low birth weight is more common among nonwhite infants, as shown in Table 4-18.

Table 4-18. — Resident births, by weight, race, and age of mother, for New Jersey, 1981

Weight and race	Percentage								
	* Total	Age (years)							
		Under 15	15-19	20-24	25-29	30-34	35-39	40-44	45 & over
Over 2,500 grams									
White	94.39	91.35	92.53	94.18	94.62	0.49	93.87	92.52	87.50
Black	86.41	78.90	85.12	87.14	86.56	95.62	85.26	83.94	100.00
Other	94.54	0.00	92.31	97.52	95.57	87.88	96.61	92.31	100.00
Unknown	7.81	100.00	12.50	10.42	8.90	93.80	8.06	6.45	0.00
1,501 to 2,500 grams									
White	4.68	8.64	6.26	4.81	4.55	3.99	4.95	6.10	8.34
Black	11.03	16.58	11.98	10.40	11.05	9.80	11.87	15.33	0.00
Other	4.86	0.00	3.58	6.71	4.09	9.80	2.25	7.69	0.00
Unknown	0.58	0.00	4.17	1.56	0.57	5.63	0.00	0.00	0.00
Less than 1,501 grams									
White	0.90	0.00	1.21	0.97	0.79	0.81	1.16	1.18	4.17
Black	2.55	4.52	2.88	2.47	2.36	2.23	2.86	0.73	0.00
Other	0.60	0.00	3.57	0.35	0.39	0.57	1.12	0.00	0.00
Unknown	0.12	0.00	0.00	0.52	0.00	0.16	0.00	0.00	0.00

SOURCE: New Jersey Department of Health 1983

*Totals do not sum to 100 percent because birth weight was unknown in 1,587 cases.

Each year, approximately 40 very-low-birth-weight infants and 170 low-birth-weight infants can be expected to have a major handicap, such a cerebral palsy, IQ below 70, severe hearing or vision loss, and other disabilities (Kern 1984).

Birth Complications

Many difficulties arise before, during, and following birth that may be causes of mental retardation.

Risks before birth include placenta previa, abruption of the placenta, hypertension, and multiple pregnancy. If these risks are identified early, intervention often can reduce or eliminate the risk.

During birth, physical injuries have become less common, but asphyxia has become more prominent as a cause of mental retardation. Adequate monitoring of the fetus and of the patient in labor can minimize risk. Electronic monitoring of the fetus and sampling of fetal blood for acidosis during labor identify fetal distress before brain damage and permit corrective action.

Following birth, complications of intensive care or inadequate intensive care can lead to brain damage. The most common neurological problem of the preterm infant is intraventricular hemorrhage, and intensive care can reduce the long-term impact on the infant of this complication.

More data on long-term outcomes of injuries at birth (and more than one may occur at the same time) are needed to show how these cause learning disabilities. For example, we said that it is not uncommon for children to be asphyxiated at birth, but most do not display negative effects from this later in life. (See our recommendation, "Follow Up Infants at High Risk.")

Many neurological problems are not understood well: learning disabilities, attention deficits, dyslexia, and hyperactivity are complex behaviors associated with normal intelligence in older children that are difficult to measure and for which causation is not understood (Fotheringham, Hambley, and Haddad-Curran 1983).

Statistical data on birth complications have not been recovered at this writing.

3. DURING CHILDHOOD

Childhood Diseases

Meningitis and Encephalitis

The Ontario Association for the Mentally Retarded recently has reviewed the question of childhood diseases and infections (Fotheringham, Hambly, and Haddad-Curran 1983). A number of infections attack the brain. Infection that affects the linings that cover the brain is called meningitis. Infection that affects the brain itself is called encephalitis.

Mental and motor disabilities, hydrocephalus, hearing loss, and abnormal speech are some of the consequences of meningitis. Problems are worse the longer the delay before detection and treatment, including reduced intelligence, mental retardation, and cerebral palsy.

Meningitis occurs in the neonatal and childhood periods, owing to organisms such as E. coli and Group B streptococcus. For New Jersey in 1984, 9 cases of neonatal meningitis (children 4 weeks old or younger) and 168 cases of childhood meningitis were reported in 1984 (Mojica 1985).

Many organisms cause encephalitis, including the bacteria and the viruses that produce influenza, mumps, chickenpox, herpes simplex, rubella, and measles. In 1984, for New Jersey, 1 case of encephalitis was reported (Mojica 1985).

Rubella and measles used to be the most common causes.

Rubella

In 1982, for the United States, 2,263 cases of rubella were reported, while for New Jersey, 18 cases were reported (Miller *et al.* 1984). In 1984, for New Jersey, 23 cases of rubella were reported (Mojica 1985).

Measles

In 1982, for the United States, 1,687 cases of measles were reported while for New Jersey, 5 cases were reported (Miller et al. 1984). In 1984, for New Jersey, 7 cases of measles were reported (Mojica 1985).

Pertussis (whooping cough), mumps, and chickenpox are now more common causes.

Pertussis (Whooping Cough)

The leading cause of bacterial meningitis is hemophilus influenzae type b. It causes approximately 12,000 cases of menigitis annually in the United States and most cases occur in children aged under 5 years. The mortality rate in this disease is 5 percent and neurologic sequelae are seen in up to 25-30 percent of survivors. The pertussis bacteria can result in encephalitis in very rare cases (Baker 1978).

Recently (April 1985) *hemophilus influenzae* type b polysaccharide vaccine was licensed and is presently recommended by the New Jersey Department of Health for all children at 2 years of age. The addition of this vaccine to our immunization program will offer significant protection against a major cause of bacterial meningitis in young children.

In 1982, for the United States, 1,895 cases of pertussis were reported while for New Jersey, 26 cases were reported (Miller *et al.* 1984). In 1984, for New Jersey, 12 cases of pertussis were reported (Mojica 1985).

Mumps

In 1982, for the United States, 5,117 cases of mumps were reported while for New Jersey, 54 cases were reported (Miller *et al.* 1984). In 1984, for New Jersey, 139 cases were reported (Mojica 1985).

Other Diseases and Infections

Herpes simplex and cytomegalovirus do not as yet have vaccines. Even where vaccines are available and effective, however, they may not reach the population in need, especially the mothers and children of the poor, where the risk of mental retardation is highest for all causes.

Epilepsy

Epilepsy is a complex and major national health problem that affects at least 4 million citizens at an estimated cost of over $4 billion annually (Funk 1974). Approximately 78,000 persons with epilepsy are scattered throughout institutions for the mentally ill and the mentally retarded.

In some cases of epilepsy, the cause is unknown and cannot be determined, but most physicians agree that epilepsy results from defects in the brain. Epilepsy is one symptom of a number of well-defined genetic diseases, but congenital and hereditary diseases and tendencies that may cause epilepsy are frequently difficult to determine.

Injury, infection, or systemic illness of the mother during pregnancy may be responsible; delivery itself can cause brain injury. Epilepsy is an occasional consequence of many of the common infections of childhood — such infections as measles, mumps and diptheria — but it is a common consequence of bacterial meningitis. Lead poisoning and head injury rank high on the list of preventable causes of epilepsy.

Many children with epilepsy, perhaps as many as 30 percent, are also mentally retarded. Frequently in their first attempts to enter the outside social world they are treated as if they are mentally inferior and incapable to maturing and living a full and normal life (Epilepsy Foundation of America 1975).

Malnutrition

The greatest single hazard to an infant is low birth weight. Maternal nutrition requires calories, vitamins, iron, calcium, phosphorus, protein, and other nutrients during the prenatal period. An infant's birthweight depends on the mother's weight before and during pregnancy and at birth. About one-third of all low birthweight in the United States results from retarded fetal growth during pregnancy, and this is attributed, in large measure, to malnutrition.

Poor nutrition for both mother and infant is linked to impaired development of the brain and to poor intellectual performance. An infant who is born at less than 5.5 pounds (2,500 grams) is most likely to be mentally retarded, have birth defects, and experience growth and other developmental problems. Infants with poor diets are more susceptible to infections that can cause illness and mental retardation (Sherman 1984).

The New Jersey State Special Supplemental Food Program for Women, Infants, and Children (WIC) has estimated that 134,310 infants and children up to the age of 5 are potentially eligible for the WIC Program. The most common nutritional risk factors among WIC children are iron, calcium, vitamin A, and vitamin C deficiencies. These are identified after screening of infants for iron deficiency anemia, height, and weight, as shown in Table 4-19.

Table 4-19. — Problems related to nutrition identifed among infants and children, for New Jersey WIC programs and for a sample chosen by the Centers for Disease Control, (CDC), 1982

Problem	Percentage for whom a problem was identified...		
	...at the first visit to the WIC program		...at follow-up visit to WIC
	New Jersey	CDC's sample of states	New Jersey*
Iron deficiency anemia	5.2	6.4	0.0
Stunted growth rate	15.5	9.8	10.1
Low weight for age	9.2	6.1	6.4
Low weight for height	5.0	3.5	3.6

SOURCE: New Jersey Department of Health 1985a

* Not all initial participants in the program continue in the follow-up program. New Jersey data are based on approximately 45 percent of clinics.

Lead Poisoning

While severe lead poisoning, with convulsions, coma, and death, has become less common than a decade ago, chronic low-level lead poisoning continues to be the major cause of childhood illness after malnutrition. Low-level lead poisoning has been associated with inability to learn (Needleman, *et al.* 1979; Needleman *et al.* 1984). It is pervasive among preschool children and is difficult to detect (Manton 1984; Tera, Schwartzman, and Watkins 1984; United States Department of Health and Human Services 1985).

A small child may be exposed to lead from peeling lead-based paint, from the air from automobile and industrial sources, and from canned food and household dust. Lead masquerades as iron in the human organism and is deposited over the short-term in the blood and over the long-term in the bones. The organism is particularly susceptible to lead in the early phases of development. Lead destroys brain cells and causes irreversible, life-long mental retardation.

It may be difficult to detect that poisoning is occurring. Complaints such as restlessness, occasional vomiting, abdominal pain, constipation, sleep disturbances, and apathy may be mistaken for signs of another illness, or for normal "growing pains" by parents. A misconception that lead poisoning is confined to poor children in urban ghettos may lead unsuspecting health professionals to overlook the possibility in laboratory and in other settings. Routine physical examinations may not provide the correct diagnosis. Even severe lead poisoning may not show up in the analysis of laboratory findings (Lin-Fu n.d.).

In New Jersey, 220,000 children aged 1-5 years are thought to risk exposure to lead poisoning from their environment, according to a formula for population density, income, housing, and locality, among other variables. At the rate of screening reported by the New Jersey Department of Health (n.d.), 32 percent of these children were tested. About 1,300 were found to have elevated blood lead levels in 1984. Detailed data for 1984 are shown in Table 4-20.

Child Abuse and Neglect

Child abuse and neglect can contribute to delayed development, behavior disturbances, permanent brain damage, and mental retardation (Neman 1984). Severe physical abuse often occurs at an age when the bones and skull are still relatively soft and can cause permanent brain damage and mental retardation, as well as broken bones or injury to major organs. Malnutrition is an almost constant factor in neglect and limits normal brain development.

Table 4-20. — Children tested and children screened for elevated blood lead and for high risk of lead poisoning, by county, for New Jersey, 1984[a]

County	Number				
	Tested	Screened	Elevated blood lead		
				High risk of lead poisoning	
			II[b]	III[b]	IV[b]
Total	**70,242**	**57,137**	**885**	**382**	**50**
Total elevated blood level (II + III + IV)	...	...	1,317		
Total high risk of lead poisoning (III + IV)	...	...		432	
Counties					
Atlantic	710	680	2	0	0
Bergen	9 33	765	12	11	0
Burlington	1,364	1,225	6	2	0
Camden	8,870	8,633	81	26	1
Cape May	7	7	0	0	0
Cumberland	1,346	1,284	3	6	0
Essex	17,930	10,760	263	146	21
Gloucester	2,769	2,760	4	5	0
Hudson	9,521	8,811	80	38	5
Hunterdon	47	42	4	3	0
Mercer	1,209	1,046	37	11	4
Middlesex	1,326	1,290	2	8	2
Monmouth	6,831	6,017	96	13	1
Morris	10	8	0	1	0
Ocean	222	210	2	5	0
Passaic	6,767	4,719	161	45	7
Salem	3	1	0	0	0
Somerset	425	350	2	1	0
Sussex	0	0	0	0	0
Union	7,513	6,659	69	31	5
Warren	675	666	0	0	0

Table 4-20. — Continued

County	Number				
	Tested	Screened	Elevated blood lead		
				High risk of lead poisoning	
			II[b]	III[b]	IV[b]
State developmental centers	1,535	994	60	30	4
Out of state	229	210	0	0	0

SOURCE: New Jersey Department of Health n.d.

[a] Does not include non-reportable blood-lead determinations performed by private laboratories or non-reportable negative results by hema-toflurometer in non-contract cities.

[b] Children are tested for combinations of lead in the blood and a substance called, "EP." Combinations of the outcomes of these tests make up the "risk classifications" II, III, and IV. "Elevated means risk classifications II, III, and IV; "high risk" means risk classifications III and IV.

Any one or a combination of abuses can affect the development of language, which is diagnostic for mild retardation; the ability to interact with others and learn; and the capacity to rear children in a nonabusive way later in life (National Association for Retarded Citizens n.d.). Poor parenting skills and lack of infant stimulation also are factors in developmental disabilities (Miller 1984).

Tables 4-21 and 4-22 indicate the type of substantiated child abuse and neglect in New Jersey: by type of incident and by perpetrator. Almost 5,000 cases of child abuse and more than 8,000 cases of neglect were documented.

These data show that it is mainly natural parents who shake, beat, or otherwise abuse, their children; or who neglect their children by failing to supervise, shelter, or feed them. Moreover, abuse happens in all socioeconomic classes, although the conditions that give rise to abuse are exacerbated among the low-income population.

Table 4-21. — Type of child abuse and neglect, for cases substantiated by the Division of Youth and Family Services, for New Jersey, 1983

Abuse and neglect*	1983	
	Number	Percent
Abuse total	**4,939**	**100.0**
Shaking, beating	1,765	35.7
Beating with instrument	1,522	30.8
Sexual abuse	896	18.1
Emotional abuse	288	5.8
Locking out or in	91	1.8
Burning	87	1.8
Cutting, stabbing	46	0.9
Strangling	41	0.8
Scalding	13	0.3
Poisoning	13	0.3
Drowning	7	0.1
Other	170	3.4
Neglect total	**8,193**	**100.0**
Lacks supervision	2,136	26.1
Unsafe shelter	1,740	21.2
Inadequate food	932	11.4
Medical neglect	896	10.9
Other physical neglect	816	10.0
Emotional neglect	562	6.9
Educational neglect	378	4.6
Abandonment	118	1.4
Congenital drug abuse	30	0.4
Poisoning through neglect	25	0.3
Other	560	6.8

SOURCE: New Jersey Department of Human Services 1984

*Up to three *types* of abuse or neglect can be recorded for each *incident*; 8,918 cases were substantiated in 1983.

Table 4-22. — Relationship of the perpetrator to the child, for cases of child abuse and neglect substantiated by the Division of Youth and Family Services, for New Jersey, 1983

Perpetrator's relationship to child	1983	
	Number	Percent
Total	**8,918**	**100.0**
Natural parent	6,983	78.3
Step-parent	546	6.1
Other	342	3.8
Other relative	273	3.1
Adoptive parent	208	2.3
Grandparent	125	1.4
Unidentified	122	1.2
Sibling	109	0.9
Babysitter	77	0.9
Foster parent	62	0.7
Institution staff	51	0.6
Teachers	20	0.2

SOURCE: New Jersey Department of Human Services 1984

Accidents

Accidents — motor vehicle accidents, falls, poisoning, drowning, and burns, in that order — are a major cause of injury to the head and spinal cord and of post-traumatic epilepsy to children aged up to 14 years (Colorado Developmental Disabilities Council 1984). Head injury is the most common form of trauma for which children are admitted to hospitals. In New Jersey, there are about 15,000-20,000 admissions with a diagnosis of head injury each year, and the largest number occurs in the age group 10-19 years (Schmitt 1984). Automobile accidents are more likely to occur to older children; falls to younger children (Annegers *et al.* 1980), but data on the relation of head trauma to mental retardation, are not adequate.

One study recovered 3,587 cases from county records during 1935-1974 that met at least the minimum criteria for head injury: loss of consciousness, post-traumatic amnesia, or skull fracture. Automobile accidents, falls, and injuries during recreation (for example, on a bicycle) account for roughly 70 percent of all injuries. Automobile accidents were responsible for "37 percent of all injuries, which include 50 percent of fatal injuries and 43 percent of severe injuries" [to the head].

The Charlottesville Prevention Council, Inc. estimates that 60 percent of children who are injured in automobiles sustain trauma to the head and face, and that one in ten suffers brain injury (1983).

Poisoning

Mental retardation can come from a child's ingesting common materials, such as medications, chemicals used for cleaning and decorating, house plants, and pesticides.

New Jersey has a state-funded Poison Information and Education Center, founded in 1983 at Newark Beth Israel Hospital. As shown in Table 4-23, about one-half the calls received concerned children aged 3 years or younger. Moreover, medications and toxins found commonly in the household or office constituted the largest category of reports.

The number of cases increases as the environment becomes more toxic. Calls to the Poison Information and Education Center numbered 30,000 in 1983 and almost 42,000 in 1984.

Outside the home, children can be exposed to poisons very easily. For instance, in 1980 in Buenos Aries, commercial diaper services treated diapers with phenylmercury fungicide. About 7,000-10,000 infants were exposed to mercury in high enough concentrations that mercury excretion in the urine of this agent, which is potently toxic to the kidneys, increased in a dose-dependent manner. (Gotelli *et al.* 1984). Mercury poisoning, with severe intellectual and motor damage, is well-known from the exposure of children to mercury absorbed by fish in Minamata, Japan and by seed grain in Iraq in 1971.

In 1983, in California, more children aged under 5 years were victims of drowning than of motor vehicle accidents. Near drownings, when a child sustains but survives irreversible brain damage, are reported to be increasing there (California Association for Retarded Citizens 1985).

For New Jersey, in 1982, 10 children aged 1-4 years and 20 aged 5-14 years were killed as passengers in motor vehicle accidents. In 1983, 2,018 children aged one to four years and 2,135 aged 5-9 years were injured as passengers in motor vehicle accidents. We do not have more detailed data on the nature of these injuries. In the absence of more detailed data, it is a matter of dispute what percentage of brain injury arises from motor vehicle and other types of accidents.

Table 4-23. — Telephone calls received by the Poison Information and Education System, by age of child and by toxins reported, for New Jersey, 1984

Age and toxin	Percentage
Age (years)	
Total	**99.80**
1 and under	9.5
1-2	23.1
2-3	19.6
3-5	10.2
5-10	4.2
10-20	8.6
21-65	23.0
65 and older	1.6
Toxin	
Total	**93.60**
Medicines	33.3
Home/office products	24.5
Plants	9.4
Pesticides	6.1
Food	4.3
Solvents	3.4
Alcohols	2.2
Gases/fumes	1.9
Industrial products	1.7
Bites/stings	1.4
Corrosives	1.4
Foreign bodies	0.9
Metals	0.4
Other	2.7

SOURCE: New Jersey Poison Information and Education System 1985

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CHAPTER 5

AN OVERVIEW OF THE COUNCIL'S RECOMMENDATIONS

The recommendations of the council are presented in detail at the end of this report. Here we present a summary of each of the recommendations in terms of the causes of mental retardation.

The council could not recommend a program for every cause, of course. Although there are literally hundreds of known causes, in many individual instances the causes remain obscure. It has been correctly said that the prevention of mental retardation must proceed by many small advances across a broad front. In recent years, many new syndromes have been discovered, most related either to birth defects that lead back to chromosome abnormalities or to inborn errors of metabolism that can be traced to single-gene abnormalities which affect brain function. However, no one of these alone accounts for a major percentage of diagnosed cases.

Studying causes, moreover, convinced the council that considerable research remains to be done. Even when a cause is discovered, it does not always follow that a practical means of prevention can be devised. For example, Down's syndrome originates during conception through faulty assortment of the chromosomes from one parent; as yet we do not know how to prevent this "nondisjunction." Research must continue into these mysteries.

In the meantime, greater impetus must be put behind those activities that apply the knowledge we already have about strategies that work. That is what led the council and its task forces to consider specific programs that it could recommend. Each detailed recommendation has these features:

1. The council recommends *programs*, in addition to policies, including a suggestion as to which agency should take the lead.

2. Each program is designed *to reach the people who are most at risk*, especially potential parents, the unborn and newborn, and the young.

3. Most of the *programs are ready to be put in place*: the causes of mental retardation and the means of prevention are understood; there are adequate data, systems of classifications, and definitions of responsibilities among agencies; and agencies, professional associations, the government, and the community could be expected to cooperate.

4. Many of the recommendations are to *expand programs that are already in place*. Some programs are already underway in public and private agencies, but should be expanded, or exist as detailed plans that await implementation.

5. For each program, a *rough cost estimate* has been included to give an idea as to what staff might be needed, what training the staff should have, and what overall revenue enhancement might be required.

List 5-1

CAUSES OF MENTAL RETARDATION AND THE COUNCIL'S RECOMMENDATIONS

1. BEFORE CONCEPTION AND DURING PREGNANCY

Organic and Environmental Conditions

CAUSE	RECOMMENDATION
CHROMOSOMAL AND GENETIC ABNORMALITIES Many conditions of mental retardation arise in the chromosomes and genes Less than 14 percent of low-income women at risk and 50 percent of other women at risk used genetic counseling services in 1983	**EXPAND GENETIC AND TERATOLOGIC COUNSELING** Expand screening programs, provide equal access to counseling services, and reach out to persons who are known to have genetic conditions
MUTAGENS AND TERATOGENS Exposure to environmental agents can affect reproductive cells (mutagens) or the fetus (teratogens) 1,287 consultations were reported for exposure to teratogens during 1982-1984	Expand teratologic counseling as a central information source and data base for consultation, referral, and follow-up; and as a resource for aggregate data on significant numbers of pregnancy outcomes

Causes and recommendations, *continued.*

1. BEFORE CONCEPTION AND DURING PREGNANCY

Organic and Environmental Conditions

CAUSE	RECOMMENDATION
ENVIRONMENTAL CONTAMINANTS Industrial and environmental toxins are suspected to affect the reproductive cells and the fetus More needs to be learned about doses and effects of toxins at different stages of human development before we risk continued or increased exposure	**DEVELOP INFORMATION ON EXPOSURE TO ENVIRONMENTAL CONTAMINANTS** Implement laws and regulations, educate the public, label products, organize sources of information, and study epidemiology and toxicity
ALCOHOL Even mild consumption of alcohol is suspected to affect critical stages in fetal development New Jersey has 135,000 women who have alcohol problems Only 5,915 of these women were in treatment in 1983	**EDUCATE PERSONS AT RISK ABOUT ALCOHOL & THE UNBORN** Coordinate state and local agencies to develop a protocol to identify women at risk, train professionals to recognize the signs of risk, and staff community-based programs with alcoholism counselors in 10 high-risk cities

Causes and recommendations, continued.

1. BEFORE CONCEPTION AND DURING PREGNANCY

Organic and Environmental Conditions

CAUSE	RECOMMENDATION
DRUGS Many drugs are known to affect the health of the newborn: even commonplace substances, such as the products of smoking affect the newborn. Illegal drugs are even more dangerous In New Jersey, 30 percent of females and 35 percent of males are smokers Before the 10th grade, 82 percent of pupils report using alcohol; 41 percent report using marijuana, and 20 percent report using amphetamines Many drug-abuse treatment programs in New Jersey have closed for lack of funds	**FOSTER NEW ATTITUDES ABOUT THE USE AND ABUSE OF SUBSTANCES** Support legislation and regulations that provide disincentives to smoking; and establish an inter-agency committee for comprehensive school health education Require insurance contracts to cover treatment of drug abuse to finance the development of treatment programs, respite care, and aftercare for drug abusers and their families

Causes and recommendations, continued.

1. BEFORE CONCEPTION AND DURING PREGNANCY

Social Conditions

CAUSE	RECOMMENDATION
ADOLESCENT PREGNANCY Pregnancy in adolescence increases the risk of premature birth, low birthweight, birth complications, and birth defects In 1983, in New Jersey, there were 4,246 births to women aged under 18 years	**REDUCE THE RISK OF ADOLESCENT PREGNANCY** Create a task force on adolescent pregnancy; expand services for family planning; and provide the curricula for family-life education and for comprehensive school health education to 611 school districts
INSUFFICIENT MEDICAL RESOURCES FOR LOW-INCOME FAMILIES While medicaid is nearly the only health insurance for low-income children, 250,000 persons with incomes below poverty are not eligible	**INSURE THE MEDICALLY NEEDY** Give priority to implementing the "medically needy" program, which extends coverage of pregnant women for prenatal and preventive care and coverage of persons who are aged under 21 years

Causes and recommendations, continued.

2. AT BIRTH

CAUSE	RECOMMENDATION
PRETERM BIRTHS Prenatal care that is inadequate increases the risk of low birthweight, birth complications, and birth defects In New Jersey, about 16 percent (15,000) of births *each year* do not have adequate prenatal care	**ENSURE FULL-TERM BIRTHS** Educate parents and professionals in the risk for preterm births and reach out to women who are at highest risk
BIRTH DEFECTS, COMPLICATIONS, AND HIGH-RISK CONDITIONS 2-3 percent of each year's 98,000 births display a serious congenital malformation, and common complications of delivery are known to affect the brain Handicapping conditions may not show up at birth, yet nearly 8 percent of high-risk infants will eventually develop a disease or a handicap Screening for "inborn errors of metabolism" and identifying high-risk *continued*	**FOLLOW UP INFANTS WITH BIRTH DEFECTS AND INFANTS AT HIGH RISK** Register all birth defects and all infants born under high-risk conditions so they can be followed up to ensure referral, treatment, case management, home health visits, and pediatric evaluation throughout the period of risk Increase follow-up programs through Special Child Health Services and through the perinatal centers *continued*

Causes and recommendations, continued.

2. AT BIRTH

CAUSE	RECOMMENDATION
BIRTH DEFECTS, COMPLICATIONS, AND HIGH-RISK CONDITIONS *Continued* births (assisted ventilation, sepsis, and seizures) produced nearly 4,000 cases in 1983 Only 1,734 were registered with the Birth Defects Registry in 1983. Most high-risk infants are never followed up after they leave the nursery	**FOLLOW UP ON BIRTH DEFECTS AND ON INFANTS AT HIGH RISK** *Continued* Use the information to measure and evaluate the impact of health-care programs and to assess new risks of mental retardation as they appear

Causes and recommendations, continued.

3. DURING CHILDHOOD

CAUSE	RECOMMENDATION
CHILDHOOD DISEASES Infections such as rubella, pertussis (whooping cough), and measles inflame the lining of the skull or inflame the brain Mental retardation and motor disabilities may result: the longer the delay between onset and diagnosis and treatment, the worse the outcome Vaccination can eliminate rubella, measles, and pertussis, but thousands of preschoolers are found to be unprotected when they enter school	**IMMUNIZE AGAINST INFECTIOUS DISEASES** Improve programs to extend immunization to all children Organize the system so as to prepare for possible use of new vaccines as they are developed Develop additional educational programs Improve the capacity of diagnostic laboratories to use the most up-to-date methods Develop research projects to identify and control infectious diseases

Causes and recommendations, continued.

3. DURING CHILDHOOD

CAUSE	RECOMMENDATION
NEED FOR PEDIATRIC CARE IN LOW-INCOME AREAS Many low-income preschool and school-age children have no regular pediatric care because they live where physicians will not locate, where health services are often hospital emergency rooms, and where transportation is inadequate Only 45 percent of the eligible children received the pediatric care available under medicaid as "Early Periodic Screening, Diagnosis, and Treatment"	**ESTABLISH A TASK FORCE ON EXPANDING HEALTH SERVICES IN THE SCHOOL SETTING** Encourage free-standing clinics in the school setting in ten school districts with high numbers of low-income, medicaid-eligible children. Elaborate on successful model programs already in place in three cities in New Jersey and other states
MALNUTRITION A malnourished infant risks reduced intelligence, Growth, and resistance to infection. A malnourished mother risks having a child with many disabilities Breast-feeding provides nutrition and immunities that formula cannot, but *continued*	**ENCOURAGE BREASTFEEDING, EXPAND THE "WIC" PROGRAM, AND PROVIDE FOR PUBLIC-HEALTH NUTRITIONISTS** For newborns: minimum standards for hospitals should be written to encourage and support breast-feeding and training of new parents in nutrition *continued*

Causes and recommendations, continued.

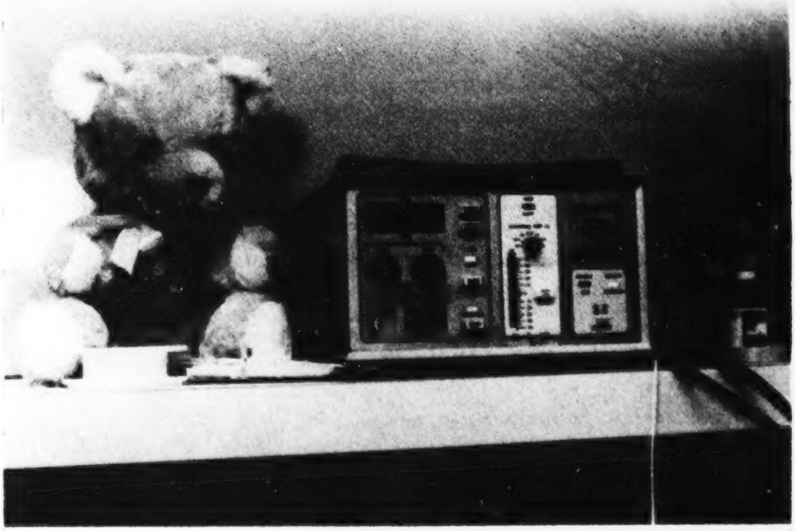
3. DURING CHILDHOOD

CAUSE	RECOMMENDATION
MALNUTRITION, *continued* hospital practices routinely discourage breast-feeding The Women, Infant, Child ("WIC") nutrition program has funds to provide food supplements to only 37 percent of eligible low-income women and children Most local health departments do not have a public-health nutritionist	**ENCOURAGE BREASTFEEDING, EXPAND THE "WIC" PROGRAM, & PROVIDE FOR PUBLIC-HEALTH NUTRITIONISTS,** *continued* For infants and older children: New Jersey should consider matching the federal contribution to the WIC program after holding public hearings on the program For all children and adults: add nutritional services to the list of requirements for local health departments
LEAD POISONING Irreversible, lifelong mental retardation menaces an estimated 220,000 preschool children who live in high-risk areas of the state Only 25 percent could be tested in 1984, but of 70,242 who were tested, *1,317 were found to be lead burdened* Sources of lead are everywhere: in paint, gasoline, drinking water, and wastes	**TEST EVERY CHILD IN HIGH-RISK AREAS FOR LEAD POISONING AND ABATE THE HAZARDS OF LEAD** Alert parents to the hazards of lead and remove lead from dwellings, gasoline, and drinking water Test every child in high-risk areas and provide resources for referral, treatment, and abatement on a sliding-fee scale Research the effects of low-level lead poisoning

Causes and recommendations, continued.

3. DURING CHILDHOOD

CAUSE	RECOMMENDATION
CHILD ABUSE AND NEGLECT Physical and sexual abuse and neglect promote delayed development, brain damage, and behavior disturbances Most child abuse is physical abuse by natural parents in the home, although child abuse may occur in day-care or in residential settings Almost 5,000 cases of abuse and more than 8,000 cases of neglect were *documented* in New Jersey in 1983	**TEACH PARENTING SKILLS THROUGH FAMILY LIFE EDUCATION** Develop a curriculum for prenatal, perinatal, and early childhood parenting Distribute this to 2,000 educators in the 611 school districts for inclusion in the curriculum of family life education that has been shown to improve parenting skills and responsibilities parenting skills and responsibilities
ACCIDENTS Accidents are a major cause of injury to the head and spinal cord and of post-traumatic epilepsy Head injury is the most common reason for which children are admitted to hospitals: 15,000-20,000 admissions per year in New Jersey In 1983, 4,153 children aged 1-9 years were injured as passengers in motor-vehicle accidents Children on school buses may not be adequately protected	**IMPROVE PROTECTION IN AUTOMOBILES** Require the use of seat belts in the rear seats of vehicles and provide stronger penalties and enforcement Coordinate safety programs, provide loaner seats for infants, and begin a statewide public campaign **IMPROVE PROTECTION IN SCHOOL BUSES** Equip all newly purchased school buses with safety belts and seats with backs of a minimum height of 28 inches



CHAPTER 6

AN OFFICE FOR PREVENTION PROGRAMS

NEW JERSEY IS AHEAD IN PLANNING

When Governor Kean asked the Association for Retarded Citizens/New Jersey to "study the issue of the prevention of mental retardation...[and to] prepare a comprehensive plan" (Kean 1984), the staff reveiwed a number of plans that have been developed by other states for preventing mental retardation and developmental disabilities.[1]

These documents tell us that New Jersey can take a leading part in a growing national movement to develop programs for prevention. What we have learned from the recommendations that are detailed in this report is that if prevention programs are to be implemented, there must be central coordination directed from the highest levels of government.

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[1] Association for Retarded Citizens/United States n.d.; Association for Retarded Citizens in Virginia *et al.* 1983; Association for Retarded Citizens of Tennessee n.d.; California Association for the Retarded 1979; Colorado Developmental Disabilities Council 1984; Florida Department of Health and Rehabilitative Services 1982; Fotheringham, Hambley, and Haddad-Curran 1983; Illinois Bureau of the Budget 1979; Maine Planning and Advisory Council on Developmental Disabilities 1983; McCormack, Briglia, and Coppola 1980; Minnesota Governor's Planning Council on Developmental Disabilities 1984; New York State Governor's Conference for the Prevention of Developmental Disabilities and Infant Mortality 1981; Poe 1982; President's Committee on Mental Retardation 1977; President's Committee on Mental Retardation and Norfolk State College 1977; Tennessee Department of Mental Health and Mental Retardation 1980; Wisconsin Council on Developmental Disabilities 1983

AN OFFICE FOR PREVENTION PROGRAMS NEEDS TO BE ESTABLISHED

When we review the details of the council's recommendations, we find that they call for programs in:

1. Research
2. Public information
3. Public education
4. Coordinated, expanded, and new services
5. Legislation and executive action

Each of these programs requires that mechanisms be developed by coordinating services among the departments and agencies outside government. Providing an office for prevention programs would fulfill the governor's order for a long-range, comprehensive plan in the most effective way precisely because it would promote coordination of services by offering information and technical assistance and by helping innovative programs to get the support that they need.

An office for prevention programs could, and should, have these functions:

1. *Encourage research.* — Our recommendations call for cooperative programs of research among departments. This requires reviewing sources of funding for biomedical, social, and behavioral research; determining how a research program could be established and funded; drafting the needed agreements, legislation, and regulations; and putting programs in place in government, in universities, and in private agencies.

2. *Develop public information capacity.* — Recommendations call for a number of public information campaigns, but the capacity for these campaigns has to be expanded in government. This requires consulting with the departments and other agencies to determine what capacities are needed in government or what contractual obligations need to be developed.

3. *Coordinate public education.* — Implementing our recommendations on education programs will require helping the departments of government and the local school districts, boards,

schools, and professional associations to work together. This means, too, coordinating with university affiliated facilities and professional associations to assess needs for professional inservice training.

4. *Stimulate expanded and new services.* — Most recommendations call for expanded or new services. For this, it is necessary to conduct a review of services in the state and private agencies that are preventive or have the potential for prevention; to survey and report on model programs from other states; and to encourage new programs by offering publicity, visibility, mobilization of community support, and technical assistance.

5. *Facilitate executive and legislative action.* — Some recommendations require changed or new legislation, regulations, standards, and guidelines. This calls for analyzing model programs from other states, fitting these to the needs of New Jersey; and seeing them introduced and followed through the legislative and executive processes.

There Already Is a Strong Interest in Planning Preventive Services

Private agencies and public agencies are strongly *committed to planning and implementing services for prevention.* We know this because the call for prevention programs came from the Association for Retarded Citizens/New Jersey, the largest private operating agency in New Jersey. When the call was made, moreover, the Department of Human Services agreed that prevention should be the program of that department (Albanese 1984), and the governor supported the concept of developing prevention services strongly in his state-of-the-state address of 1985.

Policy makers have a need for an office that could coordinate planning for prevention. Private and public agencies participate in many planning committees in and among the agencies and departments. While each has its own mandate to fulfill and none is mandated primarily for prevention, there is a potential planning network open.

Managers are in a political position that encourages an interest in prevention as an attitude. For example, now that categorical programs have been folded into block grants, there are not so many restrictions on the types of state programs as there used to be and managers are freer to try the option of newer services.

Administrators are in an economic position that can justify instituting prevention programs. Many administrators complain about "crisis management," as they run from funding period to funding period in response to laws, regulations, and internal decisions. Now that funds are being reduced and that revenue enhancement is increasingly difficult, more has to be done to use the resources that are on hand most efficiently.

Some Examples of Crucial Programs that Depend on Coordination Through a Permanent Office

1. RESEARCH

Because most of the causes of mental retardation are unknown, many of our recommendations point out the need for research.

The council's recommendations for research arose primarily from its review of the biomedical causes of mental retardation. Some needs are for research into *immunization* to identify, test for, and treat infectious diseases; to document the effects of *low-level lead poisoning;* and to confirm the suspected long-range effects of inapparent *birth defects.*

Especially crucial is lack of even the most basic information on *exposure to environmental contaminants.* New Jersey is a national leader in controlling environmental contamination, but very little is known about the thousands of chemicals that may distort human reproduction or the development of the fetus. Our agencies can take the lead in studying exposure, pregnancy outcome, and neurobehavioral, neurotoxological, and epidemiological data for industrial and commercial chemicals. We have the personnel and the agencies for this, but we need the mechanism to see it done.

Beyond the benefits of research itself, a research program coordinated by an office for prevention programs can reap three crucial benefits.

> First, funds that are not now brought into the state for research (United States Department of Health and Human Services 1982) could be brought in. We looked into the flow of federal funds to New Jersey for research on mental retardation. We found no grants for behavioral or social-science research (Tjossem 1984; Nutter 1984; Dalton 1984), and, of $8 million for biomedical research, almost none was for mental retardation.
>
> Second, a research program could provide private and public agencies with technical assistance in developing their own research programs.

Third, projects that go unfunded because they might be perceived as applying "just" to citizens of New Jersey could be carried out.

2. PUBLIC INFORMATION

Many of the council's recommendations call for information campaigns. Among these are campaigns to reach low-income families who are most at risk for *preterm births, lead poisoning, malnutrition, and childhood diseases.*

Advertising and public-relations campaigns require extremely careful and time-consuming prepartion. Media campaigns have to be prepared in a manner that forestalls any inference that they have a political intent. Materials or media programs appropriate for use in schools have to be created, collected, reproduced, or distributed for almost every program. Issues have to be coordinated with the curricular programs, classes, personnel, and policies of the schools. Current programs for training personnel and for community education have to be assessed.

An office for prevention programs can take the lead in developing central information resources, training programs, and mass-media campaigns. The departments have some public education components already — community education by departmental professionals and model programs to be used by the media, for example. But the council learned that the departments need additional resources actually to implement public information campaigns.

3. EDUCATIONAL PROGRAMS

Some of the programs that we recommend will depend on curricular programs in the schools.

The crucial problems of *adolescent pregnancy* and *child abuse and neglect*, for example, can be addressed by programs in the schools for parenting skills through *family life education* and by *comprehensive school health education*. Establishing *health services in the school setting* would complement these programs.

The Department of Education would welcome the help of many agencies to promote these programs in the schools, because local districts prefer local control and the department prefers not to mandate programs and to emphasize its academic mission.

Similiarly, the Department of Higher Education is a leader in developing a unified university system in the state that balances both public and private elements. We recommend various training programs for professionals that can combine the resources of universities, affiliated facilities, professional associations, and private agencies in an especially innovative manner.

An office for prevention programs can help agencies in cooperation with the Departments of Health, Education, and Higher Education so that local districts adopt the programs enthusiastically.

4. COORDINATION OF SERVICES

While most of our recommendations specify a "lead agency," the design, funding, staffing, operation, and evaluation of expanded and new programs have to involve extensive *coordination* with other departments and with various private agencies.

An office for prevention can develop many ways of coordination of existing services in different departments. Just a few examples:

Genetic counseling to persons in state programs

Identifying persons who are both mentally retarded and emotionally disturbed

Identifying high-risk preschoolers who live in low- income urban and rural areas

Encouraging new outreach programs by private operating agencies

Community education through hospitals

5. EXECUTIVE AND LEGISLATIVE ACTION

The council has called for executive or legislative action on a number of its recommendations. To give a few examples: new codes to control lead poisoning; new requirements for insuring the medically needy and substance-abuse treatment ordered by a physician; revenue enhancement; public hearings; and legislative, executive, or departmental commissions.

An office for prevention can be an important resource for agencies in developing laws, regulations, and protocols.

A Permanant Office for Prevention Programs

The most effective way to develop an office that can fulfill these activities is to locate it in the office of the governor, rather than of (or even in) a state department. Much of the coordination will be interdepartmental. Having the office located in the governor's office will give the leverage, the visibility, and the objectivity that are required. Moreover, such an office should be a permanent office of government.

The council has found that there are thousands of public and private agencies that offer hundreds of services to hundreds of thousands of clients. This means that there is a potential network of services for prevention.

At the state level, "14 state departments and at least 26 different divisions administer funds for services for children...educational, social, health, vocational, control and supervision, and legal representation [services]" (New Jersey Commission on Children's Services 1982).

In addition, more than 2,700 private agencies offer a wide variety of social services, some as "service-providers" for government demands, some as independent providers for citizens, and some as combinations for both (New Jersey County and Municipal Government Study Commission 1979).

An office for prevention programs can determine which of the services of these agencies can be mobilized for prevention; encourage cooperation among them; help develop common data bases and research programs; and assess and publicize the benefit costs of prevention programs.

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CHAPTER 7

EXPAND GENETIC AND TERATOLOGIC COUNSELING

RECOMMENDATION

Unborn and newborn children are at risk for birth defects that cause mental retardation from two possible sources: (1) from their parents' genetic systems and (2) from teratogens (contaminants) in the environment. These are two different sources, but screening and counseling for both can be provided and should be provided to prospective parents in New Jersey.

While New Jersey has made genetic counseling services available since 1977 and more people use counseling each year, low-income prospective parents get disproportionately fewer of these services. Genetic services are essentially preventive, yet the state spent little over $100,000 on these services in the most recent year. Screening for inborn errors of metabolism in New Jersey saves $100,000-$800,000 for each abnormality averted. Funding for genetic services should be increased.

There is growing demand for information about the effects of environmental agents on the fetus. Funding for teratology services should be increased.

The Human Genetics Association of New Jersey, Inc., and the Department of Health shoul·l develop medical service programs in the areas of genetics and teratology:

1. **Screen maternal serum for alpha-fetoprotein**
2. **Use amniocentesis when indicated by advanced maternal age and for other high-risk situations**
3. **Screen and test for fragile-X and other chromosome markers**
4. **Identify women of childbearing age who have phenylketonuria (PKU)**
5. **Expand the central information source for teratology counseling**
6. **Educate professionals and the public**
7. **Provide equal access to genetic counseling**
8. **Offer genetic counseling services to families of mentally-retarded persons who are known to have genetic conditions, who are in state developmental centers or community programs, or who are receiving any state services.**
9. **Use the birth defects registry to developed clues to the local epidemiology of teratogens in the state.**

Funding in the amount of $895,000 per year would be necessary for a period of five years. After that, there should be a reassessment to determine the financial support necessary for the state to continue to provide medical service programs to prevent genetic causes of mental retardation.

RATIONALE

Genetic and Teratology Services Programs

New Jersey has had a program for genetic services in the Department of Health since 1977. The services that are provided by the department, 20 genetic services units, and a teratology program are

1. Genetic counseling and amniocentesis
2. Screening for inborn errors of metabolism
3. Screening of newborns for hearing
4. Birth defects registry
5. Teratologic counseling

In March 1977, the Department of Health committed $40,000 in state funds to existing genetic units in the state for the support of direct service activities. In 1978, the National Genetic Diseases Act made funds available for voluntary genetic testing and counseling services, and the Department of Health was awarded $110,000 to provide citizens with information on genetic diseases and disorders. In 1982, New Jersey gave the department authority to establish guidelines and promulgate rules and regulations.

While the department funds and coordinates the local units, actual counseling and testing are available through a network of units, medical schools, and their satellites.

No resident of the state is more than one hour's distance from a genetic unit. At the core of the network are three genetic units in the University of Medicine and Dentistry (New Jersey Medical School, Newark; Rutgers Medical School, New Brunswick; and the School of Osteopathic Medicine, Camden). Each unit has a full-time medical or clinical geneticist as director, genetic counselors, and biochemical and cytogenetic laboratories. These core units in the medical schools have satellite units based in community hospitals. All community hospital units have a medical director, who is on staff at the center, and a medical-clinical geneticist consultant who is affiliated with the genetics unit of a medical school. Most have genetic counselors on staff.

Genetics Programs

Table 7-1 shows the increasing use of genetic counseling and amniocentesis. Each genetics unit reports on the services that it provides to the Department of Health (numbers and types of services; demographic information, such as county of residence, race and/or ethnic group; and method of payment: self-pay, insurance, medicaid, or medically indigent).

Table 7-1. — Genetic counseling and amniocenteses provided by genetic services units, by year, for New Jersey, 1979-1983

Year	Genetic Counseling		Amniocenteses	
	Cases	Persons	Number	Percentage change
1979	(a)	7,808	1,467	...
1980	(a)	10,178	1,805	+23
1981	2,421	8,144	2,306	+28
1982	2,701	8,506	2,864	+24
1983	3,319	9,708	3,275	+14

SOURCE: New Jersey Department of Health 1984

(a) Data were not collected in the form of cases until 1981. The change in reporting explains the apparent drop in numbers of persons in column 2.

LOW-INCOME PERSONS DO NOT GET SO MANY OF THESE SERVICES

Although more people are using genetic services, as Table 7-2 shows, when we rank counties by income, wealthier counties make more use of genetic counseling.

Table 7-2. — Utilization of genetic counseling services, by county, ranked by percentage of the population above 150 percent of the poverty level, for New Jersey, 1982

New Jersey counties ranked by percentage of population above 150 percent of poverty	Utilization of genetic services		
	High	Medium	Low
Higher income			
Morris	x		
Somerset		x	
Hunterdon	x		
Bergen	x		
Sussex		x	
Middlesex	x		
Union	x		
Burlington			x
Warren			x
Monmouth		x	
Gloucester		x	
Ocean		x	
Mercer			x
Camden		x	
Cape May			x
Salem			x
Passaic			x
Atlantic		x	
Cumberland			x
Essex	x		
Hudson	x		
Lower income			

SOURCE: Kern 1983

In fact, genetic counseling reaches substantially less than one-half of at-risk pregnant women and reaches even fewer of those who live in low-income urban areas. In 1983, Special Child Health Services estimated that services were provided to 43 percent of the population who are at risk for Down's syndrome owing to advanced maternal age. What is more, low-income women (the sum of medicaid, medically-indigent, and prenatal-clinic-based cases) had only a 14 percent utilization rate for genetic services.

TOO FEW FUNDS FOR GENETIC SERVICES

There are too few funds for genetic services for all persons to have equal access. But the Department of Health promotes the accessibility of the services to everyone in the state, regardless of ability to pay. State and federal funds are channeled to the genetic providers through the Genetic Services Program, as shown in Table 7-3.

Table 7-3. — Funding for genetic services from state and federal sources, by year, for New Jersey, 1976-1983

	Funding source (dollars)				
	State	Federal			
State fiscal year	Hereditary Disorders Program	Maternal and Child Health block grant (a)	Genetic Disease Act	Special Child Health block grant (b)	Service contracts
1976-1977	40,000	31,000	...	...	71,000
1977-1978	40,000	69,000	...	...	109,000
1978-1979	115,000	...	110,000	...	197,280
1979-1980	115,000	...	150,000	...	225,375
1980-1981	115,000	...	193,000	...	253,900
1981-1982	115,000	...	193,000	...	272,811
1982-1983	115,000	...	84,963	80,000(c)	244,950
1983-1984	115,000	...	12,200	148,480(c)	275,700

SOURCE: New Jersey Department of Health 1984

(a) Federal fiscal year
(b) Federal Maternal and Child Health block grant funds from the Special Child Health Services allocation
(c) Does not include administrative costs of the program that are picked up with the Maternal and Child Health block grant

Low funding is especially a problem because genetic services are not self-supporting since, for the most part, they are not covered by insurance (McCormack 1983b). Medical insurance generally covers services delivered in hospitals; however genetic services are delivered primarily in out-patient units. Further, while medical insurance may cover the cost of diagnosis in an *affected* person (such as an infant with a chromosomal abnormality), it will not cover the cost of screening clinically *normal* relatives of the same infant to determine possible carrier status. Finally, even when the services are covered by third-party carriers, the amount recovered under the carrier's fee schedule is often less than the cost of providing the service.

The funds for genetic counseling are a very small part — about 2 percent — of the overall program of which Special Child Health Services is a part, as shown in Table 7-4.

Table 7-4. — Allocations of federal and state dollars for Maternal and Child Health Services, New Jersey Department of Health, 1983

Allocation for Maternal and Child Health services	Dollars		
	Total*	Federal	State
Total*	**9,656,000***	**7,354,000***	**2,302,000***
Maternal and Child Health	3,028,000	2,978,000	50,000
Perinatal care	1,856,000	1,856,000	0
Primary pediatric care	1,122,000	1,122,000	0
Special Child Health	4,203,000	2,202,000	2,001,000
Ambulatory care	1,030,000	1,030,000	0
Evaluation, diagnosis, and treatment	1,030,000	1,030,000	0
GENETIC SERVICES	**257,000**	**142,000**	**(115,000)**
Accident prevention (lead poison)	1,411,000	1,385,000	26,000
Family planning	1,260,000	1,035,000	225,000
Dental health	190,000	190,000	0

SOURCE: New Jersey Department of Health 1983

*Totals do not sum from the data reported.

COORDINATION WITH THE HUMAN GENETICS ASSOCIATION

Genetic services are coordinated with the persons and agencies that provide medical genetics services. The Human Genetics Association of New Jersey, Inc., brings together the individuals who provide medical genetics services under the joint sponsorship of the University of Medicine and Dentistry of New Jersey and the Department of Health. All segments of the genetics community are part of the group: those who contract with Department of Health to provide genetics services, those who do not contract, commercial cytogenetic laboratories, college genetics instructors, interested state agencies, and other citizens.

The Human Genetics Association of New Jersey, Inc., acts informally and formally as an advisory board to the state's program; generates and reviews grant applications; and encourages public and private support for counseling, research, clinical programs, training, and education.

SCREENING FOR INBORN ERRORS OF METABOLISM

Some 45 states now have laws that require the screening of newborns for treatable genetic and chromosomal conditions of mental retardation (Levy 1984). New Jersey screens for three conditions — phenylketonuria, hypothyroidism, and galactosemia — and assesses for risk of hearing loss.

Virtually all newborns in the state are tested. A sample of newborn blood on filter paper is sent to the state laboratory in Trenton; and all abnormal results are followed up through Special Child Health Services until the presence of abnormality is either confirmed or ruled out. Table 7-5 shows confirmed positive cases for 1979-1983.

Table 7-5. — Numbers of abnormalities detected by newborn screening of live births, by year, for New Jersey, 1979-1983

Year	Live births	Abnormalities detected		
		Phenyl-ketonuria	Hypo-thyroidism	Galactosemia
1979	95,672	6	19	...
1980	96,438	9	17	...
1981	96,127	3	15	...
1982	98,225	7	22	0
1983	98,746	6	23	3

SOURCE: New Jersey Department of Health 1984

Had these children been identified *after* the clinical presentation of symptoms, and had they been just *moderately* retarded, special education costs alone for each child would have totaled at least $100,000. If the children had been so severely handicapped as to require institutionalization, the costs would have been much higher: $40,000 per year for each child — easily $1 million over a 20-year life span.

Policy in New Jersey has been to screen for conditions that are treatable, and the law permits the Commissioner of Health to test newborns for other preventable biochemical disorders (P. L. 1981, Chapter 357).

SCREENING OF NEWBORNS FOR HEARING

Every newborn in New Jersey is assessed for the presence of risk factors for hearing loss. Specific facts of the family history, the infant perinatal and neonatal course, and the presence of certain kinds of physical abnormalities are assesed. Follow-up is provided all infants at risk, including audiologic services on a sliding fee scale.

BIRTH DEFECTS REGISTRY

The Birth Defects Registry in New Jersey is an independent, population-based reporting system that has a statutory basis (P.L. 1983, Chapter 291). All children with birth defects diagnosed up to one year of age are to be reported. The administrator of the health care facility where the diagnosis was originally made is responsible for establishing reporting procedures within that facility. The registry serves the dual functions of establishing a data base for epidemiologic service and monitoring, and providing an entry point into New Jersey's service system for handicapped children.

In 1982, a total of 1,180 children with birth defects were entered into the registry, for an overall incidence of 12.25 per 1,000 live births. Many of these defects, such as chromosomal abnormalities and neural tube defects, are associated with mental retardation.

Teratology Services Program

AGENTS THAT AFFECT REPRODUCTIVE OUTCOME MAY BE MORE COMMON AS CAUSES OF MENTAL RETARDATION THAN IS COMMONLY THOUGHT

Exposure to environmental agents can affect reproductive outcome. The effect of environmental agents on the fetus is called "teratogenesis"; and "teratogens" can cause spontaneous abortions, chromosome abnormalities, altered sex ratios, reduced birth weight, developmental disabilities, and childhood malignancies (Longo 1980). Both maternal and, now more evidently, paternal exposure can have these effects.

Teratogens operate almost "clandestinely." Many environmental agents have the potential to produce functional deficits without early evidence of gross malformation. Further, effects may not be obvious until later life or may be in the form of a "mild" mental retardation *(Ibid.)*.

Teratogens may be more important causes of mental retardation than we now suspect. Our data on all developmental defects in humans suggest that about 20 percent arise from genetic conditions, 5 percent from chromosomal defects, and 10 percent from known environmental agents. This means that at least 65 percent of human prenatal developmental defects arise from unknown causes (Paull and McCormack 1980). But clinical models that use X-ray irradiation, common drugs, and ethyl alcohol suggest that a much larger percentage of developmental disabilities may very well be owing to the teratogenic effects of even common household agents (McCormack 1981).

TERATOLOGY SERVICES PROGRAM

New Jersey has had a limited teratology services program since 1982. This program has four components: (1) a data base and counseling network that counsels physicians and patients, upon inquiry, about teratogens; (2) identification and management of pregnancies at high risk; (3) education of physicians; and (4) collection of prospective data on a large number of pregnancies that are followed to term.

CENTRAL INFORMATION SOURCE

Located in the School of Osteopathic Medicine of the University of Medicine and Dentistry of New Jersey, the program has been the primary source of information on teratogens. Hospitals, health departments, physicians, and patients write and telephone for information and counseling when women are exposed to agents during pregnancy.

STATEWIDE REFERRALS

People are referred to the program by obstetricians and family physicians; genetic centers and their satellite programs; hospital obstetrics clinics and health-maintenance organizations that offer prenatal care; other medical facilities and physicians; and on their own.

About 1,300 consultations were provided in the first two years of the program, as shown in the accompanying tabulation.

AGENT	NUMBER OF CONSULTATIONS 1982-1984
Total	**1,287**
Maternal exposures	
Drugs and medications	775
Chemicals	198
Radiation	60
Maternal metabolic diseases and infectious diseases	42
Paternal exposures	9
Telephone consultations	203

SOURCE: McCormack 1984

INQUIRY, CONSULTATION, AND FOLLOW-UP

An inquiry leads to a search of print and electronic information, and files are created for the suspected teratogen. A consultation with the patient and staff is followed by recommendations on the management of pregnancy as to (1) using amniocentesis, ultrasound, or testing of alpha-fetoprotein; (2) defining risk and responsibilities; and (3) recommending or changing medications or other conditions of pregnancy. Cases are followed up as to the outcome of the pregnancy. All data are coded and added to the data base in a way that ensures anonymity.

DETERS UNWARRANTED ABORTIONS

The public and professionals are very aware of the problem of environmental contamination, but their concerns may be exaggerated in some cases. Making a parent-to-be aware that some exposure should not be overestimated does deter many unwarranted terminations of pregnancy. The program has received an enthusiastic response from the medical community, and is accumulating prospective data on substantial numbers of pregnancies that, in time, will be an invaluable resource for prevention services.

Summary

In sum, New Jersey has a need for more comprehensive services for genetic testing and counseling. Testing for more congenital defects can be done more efficiently, and more people can receive services if a more comprehensive program is developed. The programs that are in place use the resources that they have, but cannot reach enough of the population-at-risk.

Expansion of Programs

Programs for genetic services should be reassessed and expanded along the lines that follow.

COOPERATIVE PLANNING BETWEEN THE HUMAN GENETICS ASSOCIATION AND THE DEPARTMENT OF HEALTH

Comprehensive planning has to be done by a cooperative effort between the Human Genetics Association of New Jersey, Inc., and the Department of Health. We recommend developing programs out of guidelines prepared by the genetics association, which should be reviewed and approved by the New Jersey Department of Health.

1. Screen Maternal Serum for Alpha-fetoprotein

Neural tube defects, among the most common birth defects, are associated with IQs below 80 in 25 percent of cases (Holtzman 1983). Screening is necessary because 95 percent of persons with spina bifida have no family history of the disorder (Adams *et al.* 1984b; Haddow 1982; Smithells *et al.* 1983).

New Jersey could have prevented more cases of neural tube defects. In 1983, there were 55 newborns with neural tube defects registered with Special Child Health Services: *16 had anencephalus and 39 had spina bifida.* New Jersey genetic network centers screened 500 women for serum alpha-fetoprotein in 1983 (Kern 1983).

The state should establish alpha-fetoprotein screening as a routine matter, and testing should be offered to pregnant women, regardless of ability to pay. Additional funds will be needed. Laboratory testing, counseling, follow-up, ultrasonography, and treatment will incur additional costs, since a successful program requires a large-volume laboratory and specially trained personnel (Adams *et al.* 1984a). Almost any investment, however, should be cost effective.

Trends in the age of the population suggest that there will be increased demand for prenatal diagnosis among all older women during the coming years, anyway (Adams, Oakley, and Marks 1982).

With prenatal diagnosis, the risk for birth defects for women aged 35-44 years can now be reduced to a level comparable to that for younger women (Goldberg *et al.* 1979).

2. Use Amniocentesis When Indicated for Advanced Maternal Age and Other High-Risk Situations

Amniocentesis has long been shown to be effective in identifying pregnancies that are at high risk for a live birth with a chromosomal abnormality or genetic disorder (Collman and Stoller 1962; Hook and Chambers 1977). Nowadays, the maximum utilization rate for amniocentesis is estimated to be 66.6 percent. In New Jersey, 43 percent of pregnant women at risk owing to advanced maternal age have amniocentesis performed.

Approximately seven percent of births occur to women aged 35 years or more. It may no longer be appropriate to use age 35 as the definition of "advanced maternal age," however. As new prenatal diagnostic techniques are developed, such as chorionic villi sampling (a first-trimester technique), programs to utilize them should be established (Hook 1981; Hook and Lindsjo 1978; Lamson and Hook 1980).

3. Screen and Test for Fragile-X and for Other Chromosome Markers

A program should be designed to screen and test for fragile chromosome markers. Fragile-X syndrome is one of the most common causes of mental retardation after trisomy-21 (Herbst and Miller 1980). This syndrome is estimated to affect about 1 in 1,000 live births of males. At this rate, in New Jersey there may have been about 50 males born with the syndrome in 1983 alone. There is a diagnostic test for fragile-X syndrome, but the cytogenetic techniques by which the fragile-X marker can be identified have been devised only recently (Sutherland 1977), so that *most males with the syndrome have not been identified yet.*

A first step would be an outreach program to screen males who have undiagnosed moderate to severe mental retardation in a variety of settings. For example, the families of children who are enrolled in state-funded "Early Intervention Programs" might be invited to participate. Diagnostic information is always useful to a family, but diagnosis is especially helpful to *parents of young children*, who are more likely to make decisions about reproduction.

Additional program costs have to be anticipated. For instance, in this case, basic Blue Cross and Blue Shield cover diagnostic testing but do not cover counseling or testing of unaffected members of the family.

4. Identify Women of Childbearing Age Who Have Phenylketonuria (PKU)

There should be a program to identify, recover, register, counsel, and follow up women with maternal PKU. Each year, more and more women with PKU that was successfully treated in their childhood are approaching reproductive years. Many of them are unaware of their PKU or of their potential for having retarded children (Levy, Lenke, and Crocker 1979; Peterson *et al.* 1984). When these adults begin childbearing, their children will have mental retardation in 88 percent of cases, including microcephaly (75 percent), intrauterine growth retardation (30 percent), and other congenital anomalies (Hanley and Bell 1982), as the experience of other states has shown (Levy, Lenke, Crocker, 1979). These problems, collectively called "maternal PKU," often occur in offspring without the metabolic defect (Mabry 1963; Cartier *et al.* 1982; Lenke and Levy 1980; Levy and Waisbren 1983).

To extend the present program for recovering, registering, counseling, and following up women who have PKU will require additional planning and funding. In New Jersey since 1965, female infants have been screened for PKU, given effective dietary treatment, and are now normal adults but are at high risk for having children with mental retardation. These women would have to be identified and located; informed, in a noninvasive manner, of the necessity of dietary management *before* pregnancy; and protected for privacy.

5. Expand the Central Information Source for Teratologic Counseling

The Teratology Services Program should be expanded so that physicians, expectant parents, and the public receive information about the possible teratogenic effects of chemicals, infectious diseases, radiation, and other environmental agents (McCormack 1983a).

The expanded program should build on components already in place to include: (1) an on-site telecommunications network, (2) a toll-free telephone number for inquiries by telephone, (3) services to patients by experienced counselors, (4) follow-up on pregnancy outcomes, (5) educational programs, and (6) a computerized data base.

An on-site telecommunications network would provide needed access to the burgeoning information on teratogens. To be useful, the program must be able to make a thorough and rapid search of files that always are being updated, such as (1) the National Library of Medicine; (2) the Chemical Information System of the National Institutes of Health and the Environmental Protection Agency; (3) the Laboratory Animal Data Bank; (4) Bibliography Retrieval Services; and (5) Dialogue Data Base Systems.

Access is expensive and data bases continue to increase in number and complexity. Recently, for instance, computer programs for searching biomedical literature on teratology, developmental biology, and reproductive medicine have been developed (Brent 1982). Building a satisfactory data base with telecommunications requires specially trained personnel; data-processing consultations; and hardware, installations, and maintenance.

Establishing and advertising a toll-free telephone line would give more people direct access to the teratology services program. Inquiries would be accepted from both private and professional individuals who need data on a particular agent in the environment. Of course, information would be imparted by specially trained counselors to physicians. It is the responsibility of the physician to counsel the patient individually as to the risks of teratogenicity. Calls from the public and pregnant women should in no way be discouraged, however.

Providing for some compensation would make it possible to obtain needed consultation and related services and to improve record- keeping, notification, monitoring, and reporting. Services to patients are now almost "informal," since there is no regular reimbursement. A teratology consultation often requires the work of a team, on-site visits, time for evaluating information and data, and written letters and reports. Many of these services now are donated out of staff time.

Now participants are contacted soon after the expected date of delivery and the outcome of the pregnancy is determined. As the number of patients who are followed up increases, it becomes impossible to follow up beyond birth. Yet many developmental disabilities and much mental retardation present no overt signs until later in life. Where a pregnancy results in a fetal loss, too, there is an effort to ensure examination of children and fetuses by a dysmorphologist, so that at least something can be learned from a life that is lost, but more resources are needed to extend the follow-up examinations.

Training, a newsletter, and community education should be developed. First, professional training is necessary for the thousands of physicians and other health professionals who are not up-to-date on pregnancy risks, management, and policies. Since the data on teratogens change so quickly, a newsletter for professionals as to the state of the science should be circulated. Second, expectant parents need specialized information about managing pregnancies, both those at high- and those at low risk. Third, the public needs to learn about radiation, chemicals, hazardous wastes, and other teratogens in popular forums that cannot be reached by professional training or newsletters.

New Jersey already has a well coordinated genetic services network, capable of providing the most sophisticated genetic counseling and services. The network needs the experience of counselors and board-certified geneticists to develop its data base on teratogenic agents.

Among the areas that need development are a standardized data-collection plan for collecting data in a unified format and for pooling data because there are thousands of suspected teratogens; a common format for an increasing population base, compiled and synthesized for aggregate (not personal or "invasive") studies and other statistical analyses; and classifications of agents into groups that can measure the effective risks of exposure at different times in gestation and for different classes of birth defects.

Many states now are trying to implement the teratology network. For example, Pennsylvania has begun a small program based on New Jersey's; California receives 12,000 calls per year from obstetricians on a network like this; and Texas is developing a data base on a federal "Special Projects of Regional and National Significance" (SPRANS) grant. New Jersey should be prepared to join and lead this national movement.

Cooperation is possible with the New Jersey Poison Information and Education System. There is already a "hotline" for information on poisons, based at Newark Beth Israel Medical Center. The council determined, however, that a central information source for teratologic counseling would not overlap with the New Jersey Poison Information and Education System. Of course, there should be a "cooperative arrangement between the New Jersey Poison Information and Education System and the Central Information Source for Teratogenic Counseling," including the sharing of technical resource information and referral of calls (Goldstein 1985).

6. Educate Professionals and The Public

To ensure that all persons who would benefit from genetic services have access to them, there must be a strenuous effort to educate the professional and lay public about the availability of genetic services, the nature of genetic tests, and the advantages of genetic diagnoses and of genetic counseling.

At present, the genetic network is effective in providing services to individuals who refer themselves or whom a professional advisor refers. However, many at risk for having a child with mental retardation do not seek genetic counseling, because they are not aware themselves (nor are their professional advisors aware) of the potential benefits of genetic counseling. Education is needed to increase utilization of genetic services.

7. Provide Equal Access to Genetic Counseling

Since genetic counseling now reaches less than one-half of those who are eligible, and reaches low-income people (the people who may be most at risk) least of all, there should be an outreach program to extend genetic counseling to all who are eligible.

Such a program should be planned to (1) identify agencies that reach people at risk, (2) link these agencies to the three genetic services units that are located in medical schools through their satellite centers, and (3) deliver a training program so that the local agencies can *add genetic screening to their routine intake.*

Some agencies that reach people at risk include neighborhood health centers; prenatal, pediatric, and other hospital clinics; child health "conferences" (local health departments); family planning agencies; county welfare programs; agencies that provide Early Periodic Screening, Diagnosis, and Treatment services; and child protection agencies, such as the Division of Youth and Family Services.

A program to reach out to these agencies can be designed by considering the demography, location, and present services in an area; access to a provider of genetic services; and level of interest that an agency demonstrates. Initial contacts made by Special Child Health Services show that local workers will cooperate.

A training program for adding genetic screening to routine intake is possible because routine intake in agencies already includes medical history, family history, and racial and ethnic background information. What is needed is to train intake workers to recognize risk indicators, inform and refer clients, and screen for blood-related diseases.

Such a program would aim to link all agencies to the genetic services network — some 50 agencies in all. This would have to proceed by stages, perhaps adding five agencies per year for a period of 10 years, to allow for planning and evaluation.

8. Offer Genetic Counseling to Families of Persons in State Programs

A joint committee, comprised of the directors of the genetic centers based in the University of Medicine and Dentisty of New Jersey and other genetics units and representatives from the Departments of Health and of Human Services, should meet to devise a method for integrating genetic services into state programs and developmental centers. Each university center could provide services to the developmental centers in its area.

At this time, there is a pilot program in one facility to identify families who may be at high risk for mental retardation from among families with a member who is in a state supported program for the mentally retarded. A liaison should be developed for the New Jersey Department of Human Services' institutions and programs for the mentally retarded and the Department of Health's Genetic Services Program to extend this service statewide.

A network should be developed to diagnose the conditions of mental retardation accurately and to *offer* counseling to families of individuals with genetic forms of mental retardation.

Currently, about 35 percent of mentally retarded persons are thought to have mental retardation that can be attributed to either discrete genetic or polygenic causes. For this reason, accurate diagnosis of the cause of mental retardation and offering of genetic counseling services could substantially reduce the recurrence of mental retardation through, for example, prenatal diagnosis, neonatal screening, and heterozygous screening.

Some genetic forms of mental retardation are particularly tragic because each pregnancy in a family has a 50 percent risk of recurrence, yet a variety of prevention and intervention strategies goes unused. Recurrence is known to produce guilt feelings among parents who believe they have passed "bad genes" on to their children. Often, these genetic diseases are the ultimate causes of the breakups of families and marriages.

COST ESTIMATE

Funding these programs would require a yearly allocation of $895,000.

PROGRAMS	DOLLARS
Annual total	**895,000**
Expansion of genetics services	360,000
Maternal PKU	40,000
Expansion of teratology services	170,000
Equal access to genetic counseling services for families of mentally retarded persons	325,000

Expansion of Genetic Services

Services of the three major genetics centers in the state could be expanded to offer statewide alpha-fetoprotein screening. Total ongoing costs would be $360,000, with $120,000 more in start-up costs needed for the first year, as shown in the accompanying tabulation.

ITEM	**DOLLARS**
Total ongoing costs	**360,000**
Total first year costs for three sites	480,000
One time equipment costs	40,000
Ongoing personnel costs	120,000

Because most health insurance plans will cover the cost of alpha-fetoprotein screening and the subsequent workups, the level of ongoing support must cover the costs of screening and of subsequent workup for uninsured pregnant women.

Maternal PKU

The basis for a follow-up program for maternal PKU already exists in the screening program and in the case management system for Special Child Health Services. To make an effective system, one staff person would be needed to track the known cases of women with PKU and to help identify others who may have moved to New Jersey from other states. The cost would be $40,000 per year *(Ibid.)*.

Expansion of Teratology Services

The teratology services program requires $170,000. The New Jersey Department of Health commented on the costs and outcome of the proposed program:

> Using unexpended balances from the Maternal and Child Health Block Grant, such a service has been set up ($30,000 for the first year). It is expected that, as the utilization by practitioners expands, the ongoing costs of the service will increase to approximately $70,000 per year. Through a working relationship with the New Jersey Poison Information and Education Center, inquiries from the general public can be managed at no additional cost *(Ibid)*.

ITEM	DOLLARS
Total	**170,000**
Salaries	120,000
Teratologist	30,000
Genetic counselor	25,000
Data base manager	25,000
Health educator	22,000
Secretary	18,000
Fringe benefits	36,000
Telephone hotline	2,000
Equipment, overhead, and supplies	12,000

Equal Access to Genetic Counseling and Genetic Services for the Mentally Retarded

On our recommendation to expand access to genetic services, including access for the mentally retarded and their families, the Department of Health commented that these services would require program integration to reduce the costs of services for the mentally retarded and their families:

> The current genetics service network is capable of performing fragile-X determinations and other chromosomal analyses needed for an appropriate workup of...mentally retarded [persons] and their families. [Mentally retarded persons usually would have the cost of such a workup covered by medicaid. The genetic...service network would need only to integrate this effort into their general effort to reach those populations who do not now use genetic services. The recommended $250,000 to serve the genetically underserved should be sufficient to cover the costs of the effort to expand services in these two areas. These funds would be used to (1) increase the number of bilingual and bi-cultural genetic counselors by four (total cost, $160,000); and (2) cover a portion of the laboratory costs for additional genetic workups for the uninsured ($90,000).
>
> There should be funding to have at the state level, probably within the Division of Developmental Disabilities, a person or persons to coordinate and track the genetic workups of the mentally retarded persons served by the division [and coordinate education of the lay and professional communities] *(Ibid.)*

ITEM	DOLLARS
Total	325,000
Genetic counselors (4)	160,000
Laboratory costs for the uninsured	90,000
Coordinator of genetic workups	75,000

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CHAPTER 8

DEVELOP INFORMATION ON EXPOSURE TO ENVIRONMENTAL CONTAMINANTS

RECOMMENDATION

Extensive information is needed on how environmental contaminants contribute to mental retardation. The following steps should be taken to address the issue of environmental contaminants:

1. New Jersey should continue to press for prompt implementation and enforcement of the existing federal and state statutes and regulations that provide for testing chemicals for toxicity and for limiting discharges into water, air, and soil.

2. The state should expand programs to control exposure to contaminants including, but not limited to, various kinds of radiation, pesticides, carbon monoxide, and common solvents. The state should develop educational programs to inform its residents about the hazardous effects of these contaminants and about how exposure can occur.

3. Standards for labeling products so that the user can assess toxicity should be expanded. We encourage state and federal legislation would mandate this.

4. The state should conduct research and review standards on industrial and commercial chemicals.

5. State laws and regulations that control emissions into the air and contamination of surface water or groundwater and food need to be reviewed in order to assess whether these controls are adequate to prevent accumulation in body tissues over time. Right-to-know legislation to mandate this and is supported by the council.

6. New Jersey should support research on the effects of environmental contaminants by:

a. Developing and expanding the state data base on environmental exposure and pregnancy outcomes

b. Funding experimental neurobehavioral and neurotoxicity studies

c. Supporting studies of incidence and prevalence of conditions related to mental retardation and other developmental deficits in exposed and unexposed populations

RATIONALE

New Jersey, of all the states, has probably the most vigorous programs of enforcement of environmental laws to combat toxic and hazardous chemical contamination, and is nationally recognized for its efforts to identify and deal with these problems.

New Jersey's efforts to combat the problems of chemical contamination came from necessity. Our dense concentration of chemical industries, with many plants older than the turn of the century, has left a legacy of problems. Moreover, many years of illegal and irresponsible disposal of toxic wastes have left their mark.

Thus, continued vigorous enforcement of national and state laws to prevent pollution and to clean up past contamination must be maintained. Research to find better ways to deal with chemical waste is imperative.

In addition to preventing severe mental retardation, New Jersey should prevent all mental deficiencies: a reduction in intelligence capability, a developmental or learning disability, or a behavioral disorder.

The Biological Activity of Chemicals Varies Widely

SPECIES AND STAGE OF DEVELOPMENT

The effects of a biologically active substance may vary in different animal species. The type and magnitude of the effects may depend, too, on the stage of development at which exposure occurs. For example, the action of some chemicals may not be noticeable in the adult, but may cause significant changes in the developing fetus, which is very sensitive to exogenous affectors. Evidence is accumulating that many toxic substances can cross the placenta to cause exposure to the fetus.

The period when organs are developing is the most sensitive stage in embryonic and fetal development for the occurence of gross structural changes, including neurological changes. Current understanding of embryonic and fetal brain development indicates that the highest risk of mental retardation occurs when exposure comes between 8 and 16 weeks of gestation. Permanent developmental damage can occur in the newborn, too, following postpartum exposure by way of nursing and in early childhood. Even beyond the first two years of life, when the brain attains 75 percent of its adult weight, there can be damage to the brain, since biochemical changes occur over the entire lifetime.

Exposure to environmental contaminants can have adverse neurological effects on adults, including effects such as decrements in intelligence and changes in behavior. Here is a list of a few of the many chemicals that are present in the environment and known to be toxic to human neurology or behavior.

EXAMPLES OF HUMAN NEUROTOXINS

- Metals
  - Arsenic
  - Lead
  - Manganese
  - Mercury
- Pesticides
  - Organochlorine
    - Chlordane
    - DDT
    - Lindane
    - Toxaphene
  - Organophosphate
    - Demeton
    - Parathion
  - Carbamate
    - Carbaryl
  - Other
    - Thallium (metal)

- Solvents
  - Carbon disulfide
  - Carbon tetrachloride
  - Benzene
  - Toluene
  - Styrene
  - Methyl chloride
  - Perchloroethylene
- Hexane
  - Heptane
  - Methanol (and other alcohols)
  - Methyl butyl ketone (MBK)
  - Other
  - Carbon monoxide
  - Jet fuel (mixture)
  - PBBs (polybrominated byphenyls)
  - Acrylamide
  - Naphthalene

SOURCES: Anger 1984; Johnson and Anger 1983; United States Department of Health, Education and Welfare 1977; Sax 1979

DOSE

The exposure dose is another important determinant of effect. While exposure to a low level of lead may produce subclinical or subtle neurological changes, for instance, exposure to a high level may manifest itself as severe clinical disease, including encephalopathy. (See our recommendation, "Test Every Child in High-Risk Areas for Lead Poisoning....")

Overt neurotoxic effects such as changes in vision, seizures, tremor, and Parkinsonism may be found following acute exposure to neurotoxins. Behavioral effects, such as changes in reaction time, in ability to respond, and in personality indicate functional impairment at exposure levels below those that produce overt tissue or organ damage.

Studies Have Been Limited to Gross Damage, a Few Agents, or High Doses

OCCUPATIONAL NEUROTOXICITY

Exposures in occupations are frequently high and can be defined, both qualitatively and quantitatively. Effects of low-level exposures can sometimes be extrapolated from occupational data. However, most occupational data are collected on adult male populations, without considering variables such as health of spouse and children.

More recently, a new and more promising avenue has been investigated. Testing for neurological and behavioral effects of low-level industrial exposures that result in subtle clinical symptoms is a new area which has yielded important but limited information.

ANIMAL TOXICOLOGY

Animal experiments are valuable for estimating the effects of environmental agents on human health. But inferences of effects on humans present some uncertainties because of interspecies variation, and because studies are done following high doses or acute exposure. Until recently, only gross structural toxicologic effects were monitored.

BEHAVIORAL TERATOLOGY

Behavioral teratology treats pregnant laboratory animals and observes the behavior and nervous-system development of their offspring. Most chemicals have not yet been tested by the current techniques of this field: most research has studied medications. Studies of pesticides, of solvents, and of environmental contaminants other than heavy metals are rare (Vorhees and Butcher 1982).

ENVIRONMENTAL EPIDEMIOLOGY

Environmental epidemiology is difficult to study. It is difficult to identify people who are exposed to defined environmental pollutants, and subtle mental deficits are hard to identify or quantify. For example, deficits in mental development that are not associated with physical defects may not be recognized at birth since the deficit may not show up until years later. Fetal alcohol syndrome was discovered not because of its effect on brain development but because of distinctive facial and skeletal abnormalities in affected infants.

Results are available only when there has been a relatively high exposure to a defined and large population. Thus, information about toxic exposures from studies of environmental epidemiology is available for lead, where, in large, old cities, exposures are high so dose can be quantified. Other successful environmental epidemiological studies have been done on polychlorinated biphenyls (PCBs), methyl mercury, and on a few other substances.

Neurological and Behavioral Effects of Environmental Exposure

As detection methods have grown more sensitive, adverse effects of chemical contaminants have been found at lower body concentrations. Many of these physiologic changes contribute to clinical problems, including mental deficits and neurological disorders. Therefore, some data can be collected about known toxicities of various types of pollutants. In many instances, only data on high exposures in humans or on experimental testing of animals are available, as the following examples show.

HEAVY METALS

It is generally believed that most heavy metals are toxic to the embryo. Those with the best documented effects are mercury, lead, arsenic, cadmium and nickel (Leonard *et al.* 1984). Exposure can occur by breathing metallic fumes in industrial settings, breathing polluted air, ingestion of medicines, and accidental ingestion of insecticides, or of industrially contaminated or treated food and water (Oehme 1973).

Lead

Lead is the best documented environmental exposure that has been shown to cause mental retardation. The Assistant Surgeon General of the United States has recommended that all children aged up to six years be tested for lead poisoning.

Methyl Mercury

The effects of methyl mercury on humans were documented following an accidental exposure of a localized population in Minamata, Japan. Inorganic mercury contamination in Minamata Bay was converted to methyl mercury by microbes in the bottom mud of the estuary. Human exposure occurred through ingestion of contaminated fish. During the years 1953-1971, over 100 cases of mercury poisoning were reported, including 23 infants of mothers who were exposed.

The infants born during this period had high rates of cerebral palsy, chorea, ataxia, tremors, seizures, and mental retardation (Nelson 1971). Additional mercury poisonings in newborns have been reported in Nigata, Japan in 1964, in the U.S.S.R. in 1968, and in Iraq in 1972 (Koos and Longo 1976). Toxicological testing of methyl mercury on mice has shown its teratogenic and embryocidal potential, including the ability to cause major brain malformations.

Cadmium, Arsenic, and Nickel

Toxicological testing of other heavy metals, including cadmium, arsenic and nickel, has shown that they affect central nervous system development. Cadmium damages the brains of rats and rabbits when administered in the first days of life. Long-term administration of cadmium in drinking water produced degenerative changes in the nervous system including peripheral polyneuropathy in Wistar rats. Administering arsenic to golden hamsters during embryogenesis produces serious developmental malformations, including exencephaly.

While a moderately high exposure during certain stages of organogenesis may result in overt neurological dysfunction, a lower dose exposure or an exposure at a different developmental state may produce more subtle changes. For example, while exposure to methyl mercury on day 10 of pregnancy can result in overt teratologic effects (Su and Okita 1976), exposure on day 7 results in a more subtle effect. Offspring from mice exposed to methyl mercury on day 7 of pregnancy, exhibited no obvious neurological dysfunction but did exhibit subtle behavioral differences from controls at one month of age (Spyker, Sparber, and Goldberg 1972).

RADIATION

Exposure to ionizing radiation can come from natural and cultural sources, including diagnostic and therapeutic X-rays, nuclear reactors, weapon testing, occupations, and industries.

Ionizing radiation has been established as a cause of mental retardation from both animal and human studies. Evaluation of the data on radiation-related mental retardation among those exposed in the womb in Hiroshima and Nagasaki has related fetal damage to the estimated absorbed dose in fetal tissues. Within the critical period of exposure (8-15 weeks), damage, expressed as the frequency of subsequent mental retardation, appears to be directly related to the dose received by the fetus. The data are consistent with a probability of occurrence of mental retardation of 40 percent per 100 rads (Schull 1984).

In addition to directly acting on the developing fetus, radiation has been reported to cause mental retardation through genetic damage. Ionizing radiation produces gene mutations and chromosomal aberrations that, if present in the germ cells, may be responsible for the production of abnormal offspring. A chromosomal aberration is responsible for Down's syndrome. Low doses of maternal irradiation, including diagnostic X-rays taken prior to conception, have been reported to be associated with increased incidence of Down's syndrome (Alberman *et al* 1972).

PESTICIDES

Pesticides are made to be toxic to plants and/or animals, and all classes have some members with teratogenic capability. Many, including the organochlorides and organophosphates, manifest their acute toxicity through functional or biochemical action in the central and peripheral nervous systems. When tested, these pesticides have been shown to be neurotoxic and cause behavioral changes in adults (Moses 1983). Many pesticides can cause genetic damage.

Organochlorine insecticides include DDT, chlordane, aldrin, dieldrin, and lindane. They are very persistent and accumulate in the environment, resulting in a potential for chronic toxicity. The organochlorine insecticides can be classified as neurotoxins. Some of the common organophosphate pesticides (such as malathion and parathion) can alter brain electrical activity. We may therefore be concerned about their ability to affect mental development adversely.

Phenoxyaliphatic acids, a class of herbicides, are known to be contaminated at low levels with dioxins, of which TCDD (2, 3, 7, 8-tetrachlorobenzo-p-dioxin), an animal carcinogen and teratogen at very low doses, is believed to be the most toxic (Moses 1983). Most of what is known about the effects of TCDD in humans comes from occupational exposures. There have been accidental environmental exposures to TCDD in Seveso, Italy. In addition to chloracne, exposure to TCDD has been reported to cause neurological malformations, including peripheral neuropathy and behavioral changes *(Ibid.)*. While the contaminant TCDD is toxic at very low doses, at higher doses, it produces peripheral neuropathy (Goldstein, Jones, and Brown 1959).

Unnecessary or excessive aerial use of pesticides should be discouraged. Active research into the health effects and comprehensive testing of pesticides currently in use should be promoted.

CARBON MONOXIDE

Exposure to carbon monoxide (CO) may occur through vehicular or industrial emissions, home-heating sources, and smoking. Carbon monoxide competes with and displaces oxygen at the hemoglobin's oxygen binding sites. As such, it interferes with tissue oxygenation.

Studies on the effects of CO in healthy young adults support the conclusion that blood carboxyhemoglobin levels as low as 4-5 percent result in reversible adverse neurological effects, including decrements in mental function, visual acuity, and performance of vigilance tasks (Longo 1977). These levels are found in individuals who smoke one pack of cigarettes a day. The pregnant mother, the fetus, the newborn infant, as well as patients with cardiovascular and pulmonary disease, are at increased susceptibility to CO. Under steady state conditions, concentration in the fetus is 10-15 percent greater than the corresponding concentration in the mother-to-be *(Ibid.)*.

While maternal smoking presents the greatest carbon monoxide exposure to the developing fetus, the large amount of carbon monoxide produced by industrial processes, automobiles, and trucks may also have a significant role.

Ambient carbon monoxide concentrations in major urban areas and near some industrial plants are considerably higher than suburban or rural concentrations. It has been reported that high urban levels of carbon monoxide can elevate blood concentrations to levels associated with adverse neurological effects *(Ibid.)*. Prolonged low-level CO poisoning has been reported to produce personality disturbances, including irritability (Gilbert and Glaser 1959). Acute carbon monoxide poisoning has been reported for people who waited on gasoline lines during the gasoline shortage in the early 1970s. Recent evidence indicates a decrement in certain mental functions, in learning abilities, and possibly in IQ among the offspring of smoking mothers (Longo 1977).

A toxicological study of chronic exposure to low concentrations in rat fetuses supports the human data. While no overt teratogenesis was in evidence, there was a functional defect in the central nervous system of the exposed offspring (Mactutus and Fechter 1984).

SOLVENTS

Research into health effects on humans of exposure to solvents is particularly complicated. Organic solvents and their vapors are a common part of the modern environment. These include gasoline vapors, lighter fluids, spot removers, and aerosol sprays, in addition to the large quantities of solvents used in industrial settings. People are frequently exposed to a mixture of solvent vapors, the effects of which may be additive, antagonistic, or potentiating.

There have been a number of studies that show neurological and behavioral effects of solvent exposure (Baker 1983; Johnson and Anger 1983).

Inhalation of vapors of all classes of solvents has been reported to affect the central nervous system. These include the aliphatic hydrocarbons (for example, gasoline and kerosene) halogenated hydrocarbons (chloroform, carbon tetrachloride, trichloroethylene, tetrachloroethylene), alcohols (ethanol, methanol, dioxane), glycols (glycol ethers), and aromatic hydrocarbon solvents (benzene, toluene) (Cornish 1975).

Most of the data on human effects of solvent exposure come from the study of occupationally-exposed populations. There are some occupational data on health effects of a mother's exposure to solvents on the developing fetus. Maternal exposures to organic solvents have been reported to be associated with congenital central nervous system defects. The solvents include styrene, toluene, and alcohol. Animal toxicology data support the human findings (Nelson *et al.* 1979; Vorhees and Butcher 1982).

Heavy (acute) exposures can occur during furniture refinishing, fabric "guarding," and furniture spot removal. Other more chronic exposures can occur with home hobbyists (for example, for painting, silk screening, and other home crafts). It would be prudent to assume that acute and/or chronic maternal and infant exposure to solvents may have an adverse effect on mental development or mental capacity.

OTHER INDUSTRIAL AND ENVIRONMENTAL EXPOSURES

Polybrominated biphenyls (PBB) are used mainly in plastic products and fire retardants. Following an accidental addition of PBBs into the food chain in Michigan, a number of adverse health effects were noted. Studies of children conceived, born, and/or breast-fed during the period of maximal exposure indicated an adverse effect on developmental abilities (Seagull 1983; Weil *et al.* 1981). This is particularly important because adverse effects on developmental abilities were demonstrated in children exposed in the womb and in infancy.

Polychlorinated biphenyls (PCB) are compounds used in a variety of industrial applications. Following accidental high-dose exposure through contaminated cooking oils in Japan, PCBs were associated with both chloracne and systemic disease, including nausea, vomiting, weakness, and numbness of the extremities (Urabe, Koda, and Asahi 1979). PCB exposure was reported to cause birth abnormalities including eye defects. In addition, some infants breast-fed by PCB- exposed mothers developed hypotonia and apathy and appeared sullen and expressionless (Klingberg and Papier 1979). There is a possibility that contributing etiologic agents involved in the Yusho incident were dibenzofurans, which were present in the rice oil (Rosenman 1983).

One PCB has been reported to influence neurobehavioral functioning of mice during adulthood. In some cases this was observed in the absence of clinical signs of toxicity (Tilson *et al.* 1979).

PBBs and PCBs remain in human tissue for a long time. Because milk has a high fat content, these lipophilic chemicals can be transmitted to breast milk (Wickizer *et al.* 1981; Jacobson et al. 1984) Thus, mothers with polyhalogenated biphenyls are capable of exposing newborns through breast milk (Barr 1981). This ability to expose newborns through breast milk makes the effect of these chemicals on developmental abilities even more significant and compounds the many problems of exposure. (See our recommendation, "Encourage Breast-Feeding....")

Industrially important chemicals such as *vinyl chloride monomer* are common exposures in today's society. Health effects were reported following both occupational exposures and environmental exposure in people who lived near polyvinylchloride manufacturing plants. There are reports of central nervous system malformations following exposure during the first trimester of fetal development (Infante 1976).

Finally, low, chronic exposure to *carbon disulfide* has been reported to be associated with decrease in intelligence in exposed workers. Studies of exposed individuals without clinical symptoms indicate that carbon disulfide affects the working capacity and sociability of exposed workers earlier than can be diagnosed by purely clinical means (Johnson and Anger 1983).

Develop Information on Exposure to Environmental Contaminants

1. IMPLEMENT AND ENFORCE FEDERAL STATUTES AND REGULATIONS

We have various laws and regulations that are supposed to generate new data or compile existing data on *exposures* and *adverse* outcomes of exposure; and *regulate* or limit exposure by controlling production, use, or disposal of chemicals.

The United States Congress has designed a number of laws to protect the public. Five of these laws are especially important.

> *Toxic Substances Control Act (TSCA):* This law empowers the Environmental Protection Agency to require reporting of production and uses of specific chemicals and empowers that agency to require submission on intended use and probable fates of new chemicals through the Premanufacturing Notification (PMN) program.
>
> *Resource Conservation and Recovery Act (RCRA) and Superfund:* This law collects data on exposures, regulates disposal practices and cleanup activities, and provides monitoring. The law requires waste generators and disposers to provide information sources, transport, and dispose of solid waste, including hazardous waste. The law coordinates data on active and abandoned disposal sites, including degrees and types of public hazards. TSCA and RCRA together were designed by Congress to track chemicals "from cradle to grave."

The Federal Insecticide, Fungicide and Rodenticide Act (FIFRA): This requires submission of test data for registration of pesticides, specifies which pesticides may be applied, and controls the manner of their use.

The Clean Air Act and the Clean Water Act: These two laws require monitoring of air and water quality, and set limits to discharges into air and water by issuing permits that specify the quantity of certain discharges.

Overall, implementation of relevant federal legislation has been inconsistent: the agencies charged with accomplishing the statutory intents are, in many instances, years behind schedule, and some of the instruments designed by Congress for public protection have been weakly utilized or never exercised.

We recommend strong support by the New Jersey congressional delegation and participation of public interest groups and individual citizens to promote full use of the existing federal laws. Regular channels of communication between the New Jersey Departments of Health and Environmental Protection should be set up with the New Jersey congressional delegation for this purpose. A means of regular meetings would be desirable.

2. CONTROL EXPOSURE AND INFORM RESIDENTS

Programs to control exposure to and educate the public about hazardous substances should be developed. Among these programs should be these.

1. Increased educational programs for physicians and other medical workers are needed to (a) limit the use of X-rays only to those that are necessary and (b) promote the use of the best available technology so that the lowest X-ray exposure is incurred for each film. Information should be disseminated to educate women to avoid X-rays during pregnancy.

2. Educational programs should be developed by county health officers to limit the use of pesticides. There should be a special program to limit pesticide use by pregnant women and in households with newborns through the distribution of brochures available to physicians (especially obstetrical and pediatric specialists). Unnecessary or excessive aerial use should be discouraged. Active research into the health effects and comprehensive testing of pesticides currently in use should be promoted.

3. There should also be a protective public health policy on the levels of carbon monoxide in indoor, urban, and industrial air. There should be continued emphasis on prevention of smoking among pregnant women. Information about exposure to carbon monoxide and home heating sources should be made available.

4. Education programs about exposure to solvents in the home should be initiated. A review and rating of relative toxicity and safety of solvents in consumer products also should be generated and publicized by the Department of Health. These ratings should appear as labels on consumer products.

3. LABEL PRODUCTS

An evaluation for relative toxicity of consumer products should be developed, and labeling of products with these ratings should be required. There is precedent for such action in the regulation of pharmaceuticals. The data used to rate the solvents would be derived not only from currently available information but from research proposed here.

We recommend federal legislation to mandate this.

4. REVIEW STANDARDS

The state should conduct research and review standards on industrial and commercial chemicals.

5. REVIEW LAWS AND REGULATIONS

State laws and regulations that control emissions into the air, and contamination of surface water of groundwater and of food need to be reviewed to assess whether these controls are adequate to prevent accumulation in body tissues.

Statutes that are administered through state programs should be strictly enforced, and a portion of the fines collected from violations should be placed in a trust fund to help finance research.

6. CONDUCT RESEARCH

There is a major research need to determine the effect of environmental contaminants on mental development, learning disabilities, and behavior. Research is needed to detect any subtle effects and toxicities that appear late in the developmental process and to permit risk assessments for the effects of environmental exposures on mental development.

There is need, too, for characterization of the degree of risk posed by *multiple* environmental contaminants. The cumulative effect of chemical exposures may be additive or may be synergistic — much greater or much less than would be expected from the biological action of each substance alone.

There should be epidemiological studies of exposed humans and animals. *Sources of information* for understanding environmental epidemiology need to be developed. Studies of epidemiology and of experimental animals should address gaps in data. These studies should be initiated with the support of the governor.

A. Research into Epidemiology

Organize Sources of Information

New data sources should be created, and existing data should be expanded or modified to increase our ability to carry out environmental epidemiological analyses.

First, existing sources of exposure data should be computerized and organized, including:

- Permits for air and water emissions
- Fines for noncompliance with environmental laws
- Routine and special monitoring of air, surface water, and groundwater
- Industrial survey projects
- Monitoring results collected under the State Drinking Water law (P.L. 1983 Chapter 443)
- Spills reported to state emergency response authorities
- New Jersey Right-to-Know law

Second, registries on developmental outcomes should be designed and modified so that they can be used to address questions about epidemiology. (See our recommendations: "Follow Up Infants with Birth Defects," "Follow

Up Infants at High-Risk," and "Expand Genetic and Teratologic Counseling.") These include:

- Birth certificates
- Birth defect certificates
- Fetal death certificates
- Fetal defects
- Special child health services
- Genetic counseling services
- Teratology services

For example, including current and recent (last five years) addresses and/or census tracts would be valuable. A standardized occupational coding system could be used. Consistent coding on all the state registries would permit these data bases to be pooled. Existing state resources can be used for the expansion and computerization of these data sources. However, additional funds for personnel would be required.

Study Epidemiology in Local Populations

One population for research is children who are potentially exposed in the womb, during infancy, or during early childhood. These children should be tested for signs of behavioral or developmental deficits. Studies should be conducted in communities and occupational settings where acute exposures to chemicals have occurred (emergency spills and releases); or where chronic, lower-dose exposures are present (owing to persistent contamination of air, water, or soil).

The subjects for these studies might include children of men or women who are exposed to the substance in question during the year before conception, children of women exposed during pregnancy, children exposed postnatally via breast-feeding, and children who live in contaminated homes or neighborhoods. Another study population might include adults with documented exposures.

Among the available methods for evaluation of such children are psychological tests of intelligence, psychomotor development, achievement, and attention; hyperactivity ratings; neurological evaluations; performance tests; and clinical ratings.

Another type of study should include biochemical observations. Congenital central nervous system malformations (or behavioral changes at low doses) may signal the effect of environmental contaminations. Studies of these anomalies can be used to test for exposure in the womb to some chemicals. We recommend research on biochemical observations of placental tissue or of cord blood in cases of fetal deaths where congenital central nervous system malformation has occurred.

B. Research into Neurotoxicology

Consumer products and the ambient environment in New Jersey contain chemicals or mixtures of chemicals that are known to be neurotoxins but whose potential behavioral or developmental toxicity has not been adequately characterized. These substances should be tested in laboratory animals. We recommend that laboratories be funded at the New Jersey Institute of Technology and/or at Rutgers University to test questionable substances.

Some research strategies might include these:

Transport Across The Placenta or into Breast Milk

Some substances (such as methyl mercury) are capable of being preferentially transferred to the developing offspring through the placenta. Substances for which placental transport and fetal concentration have not been adequately quantified in animals should be screened to determine this important factor for potential influence on development. The degree of transport and concentration in breast milk should be determined.

Behavioral Teratology

Behavioral toxicity in laboratory animals that have been exposed in utero should be tested. This design involves exposing pregnant animals to the substance in question at various doses and examining the behavior of the offspring to develop the information needed to evaluate dose-response relationships. Teratological effects on behavior are likely to occur at doses considerably below doses that are necessary to induce visible malformations (Vorhees and Butcher 1982).

Behavioral toxicity may be caused directly by the test substance or by a metabolite of that substance. Among the assays used successfully in rodents to detect behavioral toxicity of environmental chemicals *(Ibid.)* are the ability of the animals to right themselves, to negotiate mazes, to climb ropes, to swim, and to avoid noxious stimuli.

Assays of Behavioral Toxicity in Young Animals

Not all chemicals are transported across the placenta. Neurobehavioral tests should be done on young animals to test the effect of direct exposure during infancy and early childhood. The most sensitive assays available for central nervous system toxicity to young animals should be used.

Studies of Models of Neurotoxicity

The use of animal models to assess the neurotoxicity of chemicals present in the environment is recommended, too. While the results of animal studies do not necessarily reflect the effects on humans, the use of model invertebrate systems has advantages. It is both a quick and an inexpensive way to screen for neurotoxic effects of the many chemicals and their mixtures present in the environment. This research is currently being conducted in at least one of the laboratories in New Jersey universities. Increasing state support of this research is recommended.

COST ESTIMATE

The council was unable to determine exactly what funds would be needed for these programs, since considerable design of programs would have to be done. The New Jersey Department of Health reported to the council, "We are enthusiastically supportive of proper research relating to adverse effects of environmental contaminants" (Parkin 1985).

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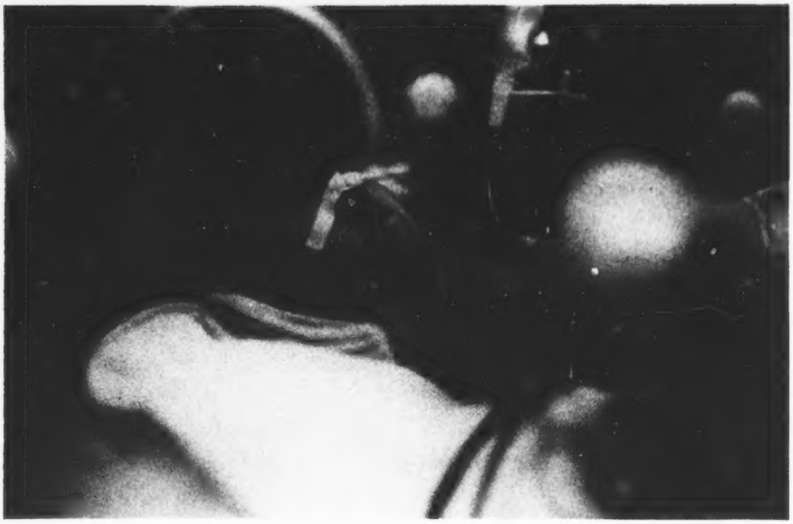

CHAPTER 9

EDUCATE PERSONS AT RISK ABOUT ALCOHOL AND THE UNBORN

RECOMMENDATION

A syndrome of birth defects is seen regularly enough in women who drink alcohol heavily during pregnancy to suggest that alcohol is responsible for the defects. The "fetal alcohol syndrome" includes central nervous system disorders; pre- and postnatal growth deficiencies; facial anomalies; and skeletal, urogenital, and cardiac disorders. The bodily expression of these characteristics is not found uniformly in the population of infants whose mothers consume large amounts of alcohol, but the association is regular enough that many professionals are convinced that there is a causal relationship. Some professionals refer to partial expressions of the clinical features as "fetal alcohol effects."

Programs to prevent fetal alcohol syndrome and fetal alcohol effects should be developed through community agencies. Components should include:

1. Coordinating the agencies that provide prenatal, perinatal, special child health, alcoholism, and drug abuse services with the Governor's Advisory Council on Alcoholism, the county alcoholism authorities, the county councils on alcoholism, the perinatal units in New Jersey hospitals, and the other relevant advisory councils, committees, and task forces

2. Developing a protocol to assess, intervene in, refer, and follow up cases of women who have drinking problems and who may become pregnant

3. Training health-care professionals to recognize women at risk of having children with fetal alcohol syndrome and fetal alcohol effects

4. Increasing public awareness about the dangers of consuming alcohol and other drugs during pregnancy

Funding in the amount of $888,429 would be necessary to implement programs aimed at preventing fetal alcohol problems.

RATIONALE

Fetal Alcohol Syndrome and Effects

ALCOHOL CONSUMPTION AND FETAL RISK

A syndrome of birth defects has been associated with alcohol consumption, defined as "heavy" drinking or "moderate" drinking.

Heavy drinking, more than four drinks per day in some studies, has been found associated with increased risk of the syndrome and its effects (Sokel, Miller, and Reed 1980; Hanson, Steissguth, and Smith 1978; Smith, Jones, and Hanson 1976); with poor muscle tone, jitteriness, and poor sucking response (Oullette *et al.* 1977); with minimal brain dysfunction (Lemouine *et al.* 1967); with increased risk of stillbirth (Kaminski, Rameau, and Schwartz 1978); and with increased risk of spontaneous abortion (Harlap, Shiono, and Ramcharan 1979). Statistically, drinking at the rate of 45 ounces per month is associated with a 40-50 percent risk of the full syndrome.

Moderate drinking — two ounces per day in some studies — has been associated with low birthweight (Kaminski, Rameau, and Schwartz 1978; Smith, Jones, and Hanson 1976; Little 1977); with decreased bodily activity (Landesman-Dwyer, Keller, and Streissguth 1978); with tremors; with poor sucking response (Martin *et al.* 1979); with spontaneous abortion (Harlap and Shiono 1980); and with suppressed fetal breathing movements (Fox *et al.* 1978). Binge drinking has been associated with brain malformations (Clarren and Smith 1978).

Findings do not support the statement that *any* amount of alcohol has effects on the fetus. "Moderate" drinking has not been consistently defined, birthweights to women who are "moderate" drinkers do not differ much from those of women who do not drink at all, and spontaneous abortion has not been found consistently in all studies (Kalter and Warkany 1983).

FREQUENCY

Fetal alcohol syndrome is a major cause of mental retardation. One estimate is that the syndrome occurs in 1-2 per 1,000 live births and that partial expressions affect 3-5 per 1,000 live births (Oullette 1983). This would have affected 3,700-18,500 infants in the United States in 1982. At that rate, fetal alcohol syndrome would follow Down's syndrome and spina bifida as the third leading congenital disorder associated with mental retardation. At this rate, as many as 200-1,000 infants might be born in New Jersey each year with the syndrome or with the effects.

Alcoholism is a Serious Problem Among Women of Childbearing Age

Alcoholism is a persistent problem among women of childbearing age. The National Institute on Alcohol Abuse and Alcoholism has reported that one in every three alcoholics is a woman. Women aged 21-25 years are found to have the highest proportions of heavy drinkers. In the United States, there are 2.25 million women and 3 million teenage problem drinkers.

There may be many cases of fetal alcohol syndrome and effects in New Jersey, but no one knows for certain because data are not collected on pregnant women or on newborns who may be affected by alcohol. As to women who have been treated for alcoholism, data have not been assembled on the numbers of these women who have been pregnant, are pregnant, have children, or on the health characteristics of their children. What is more, only nine cases of fetal alcohol syndrome were identified through the birth defects registry of the New Jersey Department of Health in 1983 (Kaslander 1985).

Alcoholism, probably, is a persistent problem among women of childbearing age in New Jersey. One study of responses to a questionnaire administered to obstetric and gynecologic patients concluded that 10 percent had alcohol problems (Sokol, Miller, and Reed 1980). The New Jersey Department of Health estimates that New Jersey has 135,000 women with alcohol problems. In 1983, 5,690 women were treated for alcoholism in New Jersey. Among these women, 70 percent were in the childbearing ages, 15-45 years, about 22 percent were black or hispanic, and 13 percent headed single-parent families (New Jersey Department of Health n.d.).

PREPARING FOR A PROBLEM

Even if fetal alcohol effects are not perfectly coordinated with alcohol consumption, many professionals take the prudent course of presuming a problem until data demonstrate otherwise, since the effects of heavy and moderate drinking have been documented.

Thus, the Surgeon General and the American Medical Association have both advised pregnant women not to drink alcohol and to be wary of the alcohol content of foods and drugs (United States Department of Health and Human Services 1981; American Medical Association 1983). Extensive research has been conducted on the problem (Streissguth and Sutherland 1979). The President declared January 15, 1984 "Fetal Alcohol Syndrome Awareness Week;" and New York City local law No. 63 (1983) requires the posting of signs where liquor is served that advise that consumption of alcohol during pregnancy may cause birth defects.

The Governor's Advisory Council on Alcoholism

One of the boards and councils of the Department of Health is the Advisory Council on Alcoholism, which includes eight citizens and the commissioners of education, community affairs, human services, labor, corrections, and health; the attorney general; and the director of the Division of Motor Vehicles.

One of its subcommittees specializes in fetal alcohol syndrome and has been carrying on professional training in conjunction with the Division of

Alcoholism and the Maternal and Child Health Program. This training includes coordinating seminars for medical and other health professionals; providing technical assistance to health professionals who wish to develop a program on fetal alcohol syndrome; making presentations to professional associations; surveying health professionals on knowledge, attitudes, and practices; responding to public inquiries; interviews with the media; providing agencies with technical information; and developing policy on treatment issues.

Table 9-1. — Allocations of funds for alcohol education and rehabilitation from the Alcohol Education and Rehabilitation Funds (P.L. 1982), by county, for New Jersey, July 1, 1984-June 30, 1985

County	Allocation (dollars)		
Total	Rehabilitation	Education	
Total	**6,064,000**	**5,298,000**	**766,000**
Atlantic	178,281	155,761	22,520
Bergen	585,176	511,257	73,919
Burlington	280,157	244,768	35,389
Camden	411,745	359,734	52,011
Cape May	82,470	72,052	10,418
Cumberland	121,887	106,490	15,397
Essex	787,107	687,680	99,427
Gloucester	175,249	153,112	22,137
Hudson	583,963	510,197	73,766
Hunterdon	60,640	52,980	7,660
Mercer	254,688	222,516	32,172
Middlesex	466,321	407,416	58,905
Monmouth	389,309	340,132	49,177
Morris	261,965	228,874	33,091
Ocean	305,019	266,489	38,530
Passaic	378,393	330,595	47,798
Salem	53,971	47,153	6,818
Somerset	131,589	114,967	16,622
Sussex	89,141	77,881	11,260
Union	392,947	343,310	49,637
Warren	73,982	64,636	9,346

SOURCE: New Jersey Department of Health 1984

Funding for activities such as these is increasing. During 1984, the state tax on the wholesale price of alcoholic beverages increased $10 million. From this will come funds for community education and information — 10 percent of the total. Each of the counties will receive a percentage of these funds to be used by the alcoholism authority that each county is required to establish. Distribution of the funds is shown in Table 9-1.

COMPONENTS OF THE RECOMMENDATION

Coordinate the Agencies

While revenue (from the tax) that can be used for education is limited, funds will be coming to the counties regularly. Activities need to be carefully planned so that the new county alcoholism authorities are able to act as effectively as possible. The council has learned that more coordination and planning is needed for these efforts. First, the *state's* educational efforts so far have centered on professionals, particularly health professionals. Second, the *county* alcoholism authorities are programs that probably need technical assistance.

We recommend that there be closer coordination of the agencies that provide prenatal, perinatal, special child health, alcoholism, and drug abuse services with the Governor's Advisory Council on Alcohlism, the county alcohlism authorities, the county councils on alcoholism, the perinatal units in New Jersey hospitals, and the other relevant advisory councils, committees, and task forces.

Develop a Protocol

Most professionals in obstetrics and gynecology have had little or no training or experience in diagnosing or working with alcohol abusers and alcoholics. A recent study suggests that clinicians miss the diagnosis of alcohol for three out of four patients (Sokol 1980). It is not standard practice to take a history of drinking, nor are health professionals familiar with resources for treatment in their communities.

To assess, intervene in, refer, and follow up cases of women who have drinking problems, a standard protocol should be developed. This would require, and facilitate, closer coordination of the agencies and organizations.

Train Professionals

Training health-care professionals to recognize women at risk and to use any protocol that is developed is the first step to making the community more aware of these problems, and we recommend that training programs be continued and systematically expanded.

A health educator from the New Jersey Hospital Association, with technical support from the state coordinator at the Division of Alcoholism and Drug Abuse Control, should develop and implement an education program to train the perinatal staff of the 63 New Jersey hospitals that provide obstetrics services and the staff of other community-based programs, such as preschool and day care programs, family planning, and so on.

Developing such a program would require a careful and complete survey of the needs, attitudes, and practices among the staff in the hospitals, and related perinatal centers, clinics, and community-based programs. This would require the work of a full-time educator for the first year. In subsequent years, this person could carry on professional training programs to train the staff of the hospitals and community programs. In future years, the established program could be implemented by a half-time health educator, possibly in conjunction with immunization education and other health promotion programs that the hospital association encourages in New Jersey hospitals. (See our recommendation, "Immunize against Infectious Diseases.")

COST ESTIMATE

The costs of such a program are estimated in the accompanying tabulation.

ITEMS	DOLLARS
Total	**45,950**
Health educator/program director	23,000
Secretary (half-time)	5,000
Fringe	5,750
Administrative costs	3,000
Equipment, supplies, and services	9,200

Increase Public Awareness

The task of increasing coordination among agencies, developing a protocol, and surveying needs for training in community-based programs should culminate in the development of positions for substance-abuse counselors in hospitals and in other centers where young women and pregnant women are seen.

COUNSELING CENTERS

These would be located in areas with high populations at risk that have been designated target cities for the reduction of infant mortality by the New Jersey Department of Health: Atlantic City, Camden, East Orange, Jersey City, New Brunswick, Newark, Orange, Plainfield, Paterson, and Trenton (New Jersey Department of Health 1985).

This program should be established in the Division of Local and Community Health Services of the Department of Health, not in the Division of Alcohol and Drug Abuse Control. There should be a coordinator to plan, monitor, and evaluate the program; staff; support; and funds for contracts to local perinatal and related services. While the program should be coordinated with the Division of Alcohol and Drug Abuse Control, it should be placed in the division that has direct responsibility for perinatal services and for services that are specifically for maternal and child health, not for alcoholism or for drug addiction.

Cooperation among programs can be facilitated because some of these cities where community-based programs should be provided with a counselor are directly in the service area of a designated perinatal center:

CITY	PERINATAL CENTER
Atlantic City	Atlantic City Medical Center
Camden	Cooper-Lourdes Medical Center
Jersey City	Jersey City Medical Center
Newark	Newark Beth Israel Medical Center University-United Hospitals
New Brunswick	Saint Peters Medical Center
Paterson	St. Joseph's Hospital
Trenton	Mercer Medical Center

Guidelines for the program could be developed in cooperation with the eleven perinatal centers, the New Jersey Hospital Association, and other relevant agencies.

COST ESTIMATES

The yearly costs of such programs are estimated in the accompanying tabulation.

ITEM	DOLLARS
Total	**$842,479**
Project officer	4,000
State coordinator	27,800
Secretary	10,579
Fringe	19,100
Programs **($71,000 for each of 11 programs)**	781,000
Counselor	30,000
Secretary	15,000
Fringe	11,000
Administration, equipment, and supplies	15,000

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CHAPTER 10

FOSTER NEW ATTITUDES ON THE USE AND ABUSE OF SUBSTANCES

RECOMMENDATION

Many drugs are known to affect the central nervous system adversely in humans. Even commonplace substances, such as the products of smoking, affect the unborn.

Social pressures encourage substance abuse among teenagers. However, this same pressure can be used to promote declines in substance abuse, delay the onset of abuse, and reduce its prevalence.

> **1. To help reduce substance abuse among young people we recommend the development of a program of comprehensive school health education. School health education should be integrated with school health services; be coordinated with federal and state health programs; and be exhaustive in covering substance abuse, disease and infection, and preventive family health.**

2. Attitudes outside the school that will help prolong the attitudes formed in school should be developed, too. We recommend that the governor support legislation to control smoking in public places, government buildings, and on buses. This will help discourage the casual use of social drugs, one of the adult models that the young imitate.

3. Finally, new attitudes should be developed by creating treatment programs for substance abusers, and especially for their families (who are particularly educable victims of substance abuse): (a) require medicaid to cover treatment of alcoholism in other than just demonstration programs; and (b) require private insurers to cover treatment of drug abuse when it is prescribed by a physician.

RATIONALE

Taking in Chemical Substances is Routine for Most of Us

People in our society are encouraged to medicate themselves. This easily leads to over medication. For example, even in the special state of pregnancy, pregnant women use, as a mean, some ten drugs during pregnancy (Swaab and Mirmiran 1984).

But drugs taken in pregnancy can affect the unborn. Only 18 percent of drugs and of inert substances used in drug formulations have had enough testing to permit a complete assessment of the health hazards, not including "behavioral" (or "functional") birth defects (National Research Council 1984). A study of 4,428 deliveries in Connecticut found that 44.5 percent of all mothers used at least one prescribed drug during pregnancy, "a 30 percent increased risk for delivery of a congenitally malformed infant" (Bracken and Holford 1981). A study of collaborative data found that exposure to barbituates during pregnancy elevates learning disabilities in children by 13 percent (Nichols and Chen 1981).

Even Commonplace Substances Affect the Unborn

Again, smoking can be considered a form of medication. Consider how commonplace smoking is: one third of all women in the childbearing years are smokers, and their numbers are increasing (Steinfeld 1983). More than one-half of women who become daily smokers take up the habit before their ninth grade of school (Johnston, Bachman, and O'Malley 1977).

Yet even so commonplace a social drug affects the unborn. Smoking affects the development of the central nervous system. Perhaps by impairing oxygen delivery, smoking decreases birthweight in direct proportion to the number of cigarettes smoked; smoking increases the risk of spontaneous abortion or neonatal death; and increases serious complications in the mother (American College of Obstetricians and Gynecologists 1979). Lower IQ scores, reading disorders, and hyperactivity among the offspring of smokers suggest damage to the central nervous system in the womb *(Ibid.)*.

Smoking may affect the fetus through the father. Sperm samples from smokers have been found to display a greater percentage of abnormal forms (Evans *et al.* 1981). Chromosomal aberrations have been reported for heavy smokers (Obe and Herha 1978; Lambert *et al.* 1978; Yamaski and Ames 1977). A study of the smoking habits of fathers of 5,200 infants showed increased perinatal mortality when the father smoked even if the mother did not (whatever the age of the parents; the number of births; the socioeconomic characteristics of the parents; or the history of abortion, miscarriage, or stillbirths). Children of fathers who smoked heavily displayed about twice the expected incidence of severe malformations (Mau and Netter 1974).

Substance Abuse Begins Among the Young

The casual attitude to substance use that leads to unnecessary and dangerous use affects the young. In fact, a major problem of substance abuse exists among youth throughout the state. Fisher (1984) surveyed students in grades 10-12 on their substance use. At the time of the survey, 66 percent had used alcohol during the past month, 29 percent had used marijuana, 12 percent had used amphetamines, and 8 percent had used cocaine (Fisher 1984). The students reported that before reaching the 10th grade in school, 82 percent had used alcohol, 41 percent had used marijuana, and 20 percent had used amphetamines.

SOCIAL PRESSURE CAN PROMOTE SUBSTANCE ABUSE

Substance abuse begins at young ages and is encouraged by social pressure. This can be shown for smoking (Evans 1976) and for alcohol and drug abuse (McAlister 1979). Younger children are almost invariably strongly moralistic about smoking (McAlister, Perry, and Maccoby 1979). They express the opinions of their parents and of parental figures (social pressure). But older children are more conscious of the opinions of their peers (social pressure) as to what is perceived as glamorous, tough, or grown-up. Thus, they are more relativistic and tolerant about substance abuse (Schneider and Van Mastrigt 1974).

This vulnerability of adolescence to social pressure is one reason that the "gateway" drug changes from generation to generation. Drug and alcohol abuse follow closely on tobacco misuse (Johnston, Bachman, and O'Malley 1977). There is a high co-incidence of smoking with the use of other drugs: those who report greater use of alcohol and marijuana also report greater use of smoking. But, where smoking may have been the drug of initiation for an older generation, alcohol may be the drug of initiation for the current generation of youth.

SOCIAL PRESSURE CAN ALSO REDUCE SUBSTANCE ABUSE

But declines too, in substance use, can be demonstrated to result from social pressure on the young. For instance, reports of perceived health risks are followed by significant declines in cigarette smoking among young people. This does not arise from their perceiving the danger of cancer or heart disease, the danger primarily to themselves; but from their need to be perceived by others as healthful and visibly atheletically fit.

Comprehensive School Health Education

One of the best ways to form attitudes among young people is to develop them in the schools. Training in school programs to resist social pressures to use tobacco, alcohol, and drugs can delay the onset of abuse and reduce prevalence among students in school programs (McCalister *et al.* 1980).

Comprehensive health education is:

- integrated with school health services
- part of efforts to generate a healthy school environment.
- coordinated with health and educational professionals at federal and state levels
- a means to stimulate understanding of the physical, emotional, and social dimensions of the sudents health
- compatible with the overall school program
- a way to explore specialized health topics of a wide variety, including

> alcohol and drug abuse; nutrition; cancer; heart diseases; and other chronic illnesses; eye health; safety; communicable diseases; disabilities; family and community health; and the importance of rest, cleanliness, and exercise.

SCHOOL HEALTH EDUCATION IN NEW JERSEY NEGLECTS THESE NEEDS

School health education in New Jersey, although mandated, continues to be "categorical" in design rather than comprehensive. "Categorical" programs come from specific laws and regulations that require health education on certain topics such as family life, drugs, alcohol, and tobacco. This means that school health programs are fragmented and important health subjects are not fully covered.

Further, in many school districts, health education is combined with physical education. Physical education gets the lion's share of the scheduling time.

MANY AGENCIES RECOMMEND COMPREHENSIVE SCHOOL HEALTH EDUCATION

During the past decade, there have been a number of initiatives at the state and national level that have advocated a comprehensive, rather than a categorical, approach to school health education. Examples include a statewide conference in 1978 sponsored by the University of Medicine and Dentistry of New Jersey; a 1980 School Health Education Study Committee established by Frederick E. Burke, Commissioner of Education on the recommendation of Commissioner of Health Joanne Finley; the 1980 national Conference on Health Promotion in the Schools; the New Jersey School Health Education Review Committee established in 1981, and experts in the field consulted by the United States Department of Health and Human Services on the health needs of school-age children and adolescents (United States Department of Health 1981).

CURRICULA HAVE ALREADY BEEN WRITTEN

There are a number of curricula that have been implemented in schools nationally, but one has gained unprecedented acceptance by 595 school districts in 41 states. The *Growing Healthy* comprehensive school health education curriculum has been designed for students K-7. The model has been in the process of development, evaluation, and implementation since 1969. The *Teenage Health Teaching Modules* program for junior- and senior high-school students, which reinforces the curriculum covered in the elementary grades, has been introduced in 63 school districts in Colorado. Some 10,000 teenagers have been trained through at least one of these 16 modules since October 1982 (National Center for Health Education 1984).

A COMMITTEE FOR COMPREHENSIVE SCHOOL HEALTH EDUCATION

A statewide, interagency committee for comprehensive school health education should be established by the governor to provide direction for school health education in New Jersey. This committee would work in six steps:

1. *Survey school health education* in New Jersey to identify the content areas included in current curricula and to determine how the content areas are integrated into curricula

2. *Coordinate with the Departments of Health, Human Services, and Education* to develop a common plan for school health: (a) a comprehensive plan to integrate and coordinate school health services with school health education; and (b) plans for implementating, monitoring, and evaluating programs

3. *Request the State Board of Education* to encourage the separation of health education from physical education

4. *Identify sources of technical assistance,* in-service programs, and related materials in health education that could be provided by various health agencies in New Jersey to update the knowledge base of teachers and districts

5. *Encourage technical assistance through the Departments of Health, Human Services, and Education* to provide and recommend sources of technical assistance to districts

6. *Identify funding* that would help districts implement their programs

REVENUE FOR SCHOOL HEALTH EDUCATION

The taxing of cigarettes and of alcohol could not just generate new state revenues but could provide a disincentive to the use of these subtances (New Jersey Interagency Council on Smoking and Health 1984). One use of these resources would be to reach more adolescents and teenagers through school health programs for teenagers.

Controlling Social Drugs

Attitudes *outside* the school will have to change if school programs are to be effective, in the long run. The routine, casual use of social drugs among adults is a model that adolescents imitate. But now there is a growing public desire to restrict the routine, casual use of drugs. Among these is nicotine, and there is a growing, public desire to restrict public smoking.

Evidence is increasing to suggest that a nonsmoker may have unintended effects from a neighbor's smoking (Reichman 1984). More regulation of smoking in public places has been called for, and we think it is a good idea to support citizens in this matter.

The governor has supported legislation to control smoking in the workplace, in certain restaurants, and in certain retail food and marketing stores. The governor should support legislation to control smoking in government buildings, in public places, and on buses. This would encourage change in social attitudes to smoking.

Providing Treatment Programs

A third way to develop new attitudes is through the treatment of substance abusers and their families. Besides changing the attitudes of substance abusers, treatment programs can educate the non-abusing victims of substance abuse. This component of "Alateen," for example, has been shown to have a strong preventive impact. Many youth groups could be mobilized to participate benefit from the spill over of community education through substance abuse treatment.

NEW JERSEY HAS FEW PROGRAMS

New Jersey does not have many resources for treating drug and alcohol abuse, however. In fact, each year, New Jersey sends 400 children to Pennsylvania for treatment programs that it cannot provide at home.

New Jersey needs sufficient services to develop a "continuum of care": in-patient, out-patient, and aftercare; transitional living facilities; and long-term living arrangements. There are too few programs to treat those who live with someone who abuses alcohol or drugs, and the lack of these often forces clients into inappropriate and more expensive treatment.

NO FINANCIAL BASIS FOR PROGRAMS

There are few non-hospital-based facilities for treatment because there is no reimbursement for services. Cutbacks in federal funding have forced the closing of a number of non-profit agencies that specialized in treating drug abuse. In addition, reimbursement for non-hospital-based services by medicaid and by private insurers varies for different substances. For example, the recent enactment of P. L. 1984, Chapter 86, covers treatment of *drug abuse* in free-standing residential treatment settings by medicaid; but treatment of *alcoholism* in these settings has been covered by medicaid only in demonstration projects. Again, private insurers have been required by law to treat alcoholism since 1977, but they are not required to cover treatment of *drug abuse*.

The cost of medical treatment is high, but there is no reimbursement available. So, there is no incentive for providers to develop facilities.

1. Medicaid should be required to cover treatment of alcoholism in free-standing treatment centers in more than just demonstration projects.

2. Private insurers should be required to cover treatment of drug abuse when this is prescribed by a physician.

Cost Estimate

A budget request for two years for a committee to work on comprehensive school health education would be $200,000 per year, to establish the committee, conduct a survey of school health education curricula, and design an implementation strategy for the New Jersey schools. We have not estimated the costs of developing new treatment programs.

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CHAPTER 11

REDUCE THE RISK OF ADOLESCENT PREGNANCY

RECOMMENDATION

Pregnant adolescents are at risk for delivering premature or low-birth-weight infants, and low birth weight is one of the conditions commonly associated with mental retardation. In New Jersey *in just one year,* 1983, there were 7,170 births to women aged 18 years and under.

There has been a growing pattern of increased sexual activity at younger ages. The social and economic reality is that it is not very likely that this trend in sexual behavior will change. However, it is clear that the incidence of adolescent pregnancy can be reduced through the ready availability of contraceptive materials and information, counseling and education to encourage appropriate choices for their future, and family life education to make it more likely that children will delay their sexual activity until they are emotionally able to manage its consequences.

The rate of adolescent pregnancy can be reduced:

Family life education causes adolescents to delay their sexual activity or to delay a second pregnancy if they have already been pregnant (Sex Education Council of the United States 1982; Alan Guttmacher Institute 1981).

Enrollment in family-planning clinics has been shown to reduce the rate of pregnancy and the rate of births among teenagers (Forrest, Hermalin, and Henshaw 1981).

With appropriate prenatal care, the situation and outcome of births to teenagers, and of their children, can be improved (American College of Obstetricians and Gyneclogists 1982).

Even as "children continue to bear children," we can lessen the resulting mental retardation, ill-health, or poverty. To achieve these goals, we recommend that:

1. The governor should support creation of a "Task Force on Adolescent Pregnancy." Companion bills in the senate and assembly call for a blue-ribbon task force of public and private leaders to study, assess, and act on services and collaborative activities both to prevent pregnancy and to provide services for teenage parents.

2. The governor should allocate funds for programs in prevention, services, and cooperative planning. The New Jersey Network on Adolescent Pregancy and the New Jersey Network on Family Life Education are examples of cooperative planning organizations that should have continuing support. Model programs exist in the areas of family planning and community support services that should be replicated throughout the state. Monitoring and evaluation components should be built into these new activities as part of their program elements.

3. Both family life education and comprehensive school-health education must be given priority for implementation in the public schools. Comprehensive planning and evaluation of model programs have to be part of the background work for this.

RATIONALE

7,170 Births to Teenagers in 1983

About 1 out of 10 girls in New Jersey gets pregnant sometime during the adolescent or teenage years. In 1983, 7,170 girls aged 18 years and under gave birth in New Jersey. Roughly, this means that almost 58 percent of teenage girls who get pregnant choose to carry their infants to term.

Yet, the odds that the child of a teenager will be permanently damaged are 40 out of 100. Many adolescent mothers go without adequate prenatal care. This puts them and their infants at high risk.

Disability, Abuse and Poverty Results

COMPLICATIONS IN PREGNANCY

Pregnant young adolescents are at increased risk of complications in pregnancy: bleeding, anemia, prolonged labor, need for cesarean section, toxemia, sexually- transmitted diseases, and cervical cancer (Brookman 1983).

DISABLED CHILDREN

Their children are at increased risk for premature birth, low birthweight, neonatal mortality, neurological deficits, and sexually-transmitted diseases (McCormick, Shapiro, and Starfield 1984). Mayor Koch's Task Force on Special Education in New York Schools reported in 1984 that children of teenage parents are disproportionately found in special education classes.

CHILD ABUSE

Teenagers do not have the maturity and experience to be effective parents. This results in physical neglect, inadequate nutrition, inattentiveness to health care needs, and serious maltreatment (Child Welfare League of America 1983; Bolton 1982).

CHRONIC POVERTY

Teenage parents frequently end up in chronic poverty. Five out of ten teenage mothers never finish high school, six out of ten will be supported by public assistance, and as many as five out of ten will have a second pregnancy within two years (Alan Guttmacher Institute 1981). Teenage pregnancy may be the largest single cause of welfare dependency after age and disability (New York State 1983). Teenage parents have great difficulty getting employment and have long periods of unemployment (McGee 1982).

UNBREAKABLE CYCLE

The children of teenagers are liable to carry on the patterns they learn by repeating teenage pregnancy in successive generations (Brookman 1983; Dryfoos 1985).

Our Society Gives Mixed Signals about Sexuality and Parenting

Our society increasingly undermines the supports that make rearing a *family* possible. Adolescents have been having children for millions of years. In the past, however, young parents could count on kinsmen for help and support since most people were confined, for their lives, to small villages. But the modern world stresses each person's obligations to a much larger society; divides each person among many competing loyalties; asks that each person participate in political, civic, and community life; and increasingly requires *every* family member to work outside the home to survive.

There actually are forces in our society that encourage teenage pregnancy. Some adults encourage pregnancy by their high regard for childbearing within the adolescent's family and community. Other adults "encourage" sexual activity by pandering, for example, through the media (Plaghoft and Anderson 1981). Other adults encourage pregnancy by their negligent or forbidding attitudes: for example, teenagers may not use contraception because the puritanical attitudes of adults may discourage education about sexuality and threaten teenagers with public censure and punishment for seeking contraception.

Under these conditions, teenagers get pregnant for a variety of reasons. The greatest increase has been among white, middle-class teenagers (Brookman

1983; Alan Guttmacher Institute 1981). Without family supports, and yet under pressure to achieve, teenagers are more lonely, insecure, angry, and competitive than ever. They want to be adults, which, for many, is defined as having an opposite-sex partner and having children.

It may be unrealistic to expect the incidence of adolescent sexual activity to decline. Society is not going to return to small villages, interdict its pandering, or change its public posture. Increasing "permissiveness" in the media shows that pandering will not decline. The controversies around family life education, contraception, and abortion show that public postures may become increasingly forbidding.

We Know What Helps

Some programs are known to address the problems raised by teenage sexual behavior and teenage pregnancy.

PRIMARY PREVENTION: PRIOR TO PREGNANCY

Every School District Needs a Family Life Education Program

Family life education can help adolescents delay their sexual activity and delay the decision to become parents. If they are already pregnant, it can help them delay a second pregnancy. (Sex Education Council of the United States 1982; Alan Guttmacher Institute 1981).

Family life education has been required by the policy of the State Board of Education for all New Jersey's 611 school districts since 1983. However, each district had the responsibility to develop and implement its own program over a two-year period. The programs are not now all uniformly implemented. The council has made a separate recommendation for family life education, and assessing the effort will take a long time.

Family Planning Should Reach More of Those at Need

Enrollment in family planning services has been shown to reduce the rate of pregnancy and the rate of births among teenagers. (Forrest, Hermalin, and Henshaw 1981). Family planning services are available from the New Jersey

Department of Health, through a variety of agencies. In 1983, these provided 70,064 women with family planning services. Of these 34,111 were adolescents and teenagers (New Jersey Department of Health 1983).

Table 11-1. — Numbers and percentages of women who are at risk of unintended pregnancy, who need family planning services, who receive services, and who do not receive services, for women aged 13-19 years and 20-24 years who have incomes 200 percent below poverty, by county, for New Jersey, 1983

County	In Need of Services	Served			Unserved	
		Total	Adults	Teens	Number	Percent
Total	**363,300**	**89,747**	**58,883**	**30,864**	**272,603**	**75**
Atlantic	11,670	3,352	2,135	1,217	8,318	71
Bergen	26,320	7,163	4,829	2,334	19,160	73
Burlington	17,540	1,867	1,142	725	16,673	89
Camden	27,040	4,671	2,597	2,074	22,369	83
Cape May	3,850	1,642	1,031	611	2,208	57
Cumberland	8,980	2,073	1,195	878	6,907	77
Essex	62,130	19,416	13,401	6,015	42,714	69
Gloucester	10,730	1,969	1,133	836	8,761	82
Hudson	38,310	11,155	8,628	2,527	27,155	71
Hunterdon	2,500	1,138	634	504	1,362	54
Mercer	16,850	4,184	2,572	1,612	12,666	75
Middlesex	24,950	5,168	3,341	1,827	19,782	79
Monmouth	21,910	4,925	3,252	1,673	16,985	77
Morris	12,740	6,330	4,121	2,209	6,410	50
Ocean	13,020	3,791	2,360	1,431	9,229	71
Passaic	26,000	2,883	1,734	1,149	23,117	89
Salem	3,650	656	303	353	2,994	82
Somerset	6,400	1,854	1,223	631	4,546	71
Sussex	3,820	1,488	864	624	2,332	61
Union	21,160	2,392	1,342	1,050	18,768	77
Warren	3,730	1,630	1,046	584	2,100	56

SOURCE: New Jersey Department of Health.

New Jersey Needs to Reach More Than Just 24 Percent of Low-Income Women

While the cost effectiveness of family planning services has been demonstrated many times, the question that remains is whether public services can have sufficient resources reach to all the population at risk.

In 1983 state- and federally supported family programs served 30,864 teens of this target group, or just 24.8 percent of the total estimated adolescent population in need, as shown in Table 11-1. Based on studies by the Alan Guttmacher Institute, there are 124,250 adolescent women under 200 percent of the poverty level in need of family planning services in New Jersey. These programs served a total of 106,000 women at a total cost of $11.6 million, or $110 per woman served. Of all funds spent on family planning services that year, state funds ($95,443) accounted for 0.8 percent of the funds available. Local fund raising efforts accounted for 7.8 percent, medicaid 5.2 percent, patient fees 20.3 percent and *federal grant funds 61.4 percent.* Without more funding from the state for this primary prevention service, it is doubtful that a greater percentage of the high-risk population can be served.

Cost Estimate

A program to provide family planning education and services to 10,000 at risk adolescents should be a major initiative. The projected cost would be $1,000,000 (Halpin 1985).

SECONDARY PREVENTION: ONCE PREGNANT

With appropriate prenatal care, the situation and outcome of births to teenagers, and their infants can be improved (American College of Obstetricians and Gynecologists 1982).

Comprehensive programs that include education, infant day care, services to teenage fathers, job training and placement, and health services and parenting education and child care have been shown to provide the highest rate of success in enhancing the "quality of life" for teenage parents and their infants (Alan Guttmacher Institute 1981, McGee 1982, New Jersey Network on Adolescent Pregnancy 1984).

These programs have so long been expected to address the problem that they are mandated by federal and state legislation and regulation.

Maternal and Infant Care Projects (MIC) have been funded through the Maternal and Child Health Program of the New Jersey Department of Health. Through contracts with local programs, comprehensive prenatal care and infant care services are provided to high-risk, low-income adolescent mothers. These programs combine obstetrical care for the mother and pediatric care for the newborn with social service support, family planning services, and nutrition services that include food supplements.

Comprehensive programs to address adolescent pregnancy are being designed or implemented in increasing numbers as adolescent pregnancy becomes an increasingly important and recognized issue. For example, there is an Office of Adolescent Pregnancy Programs in the United States Department of Health and Human Services (1980); three "grant networks" supported by the Charles Stewart Mott Foundation; and a host of other public and private grant-supported programs such as outreach to high-risk inner-city young, prenatal care, infant care, counseling and referrals, home-based services, job-training and placement, resources identification, nutrition information and counseling, vocational training, and infant care.

Need for Planning, Comprehensive Services, and Community Education

It seems clear, then, that New Jersey needs to plan and evaluate how it can improve services for pregnant adolescents and teenagers on a comprehensive basis.

PLANNING

A Task Force on Adolescent Pregnancy

Both public and private initiatives must address the problem. The group that is most affected — underage mothers — does not have the political and economic power to represent itself. Many agencies collect data and provide services that address pregnant adolescents and teenage parents, and their work needs to be coordinated.

First, as to the *public initiative*, New Jersey proposes establishing a legislative task force that will study adolescent pregnancy and make recommendations about public action.

We think that a planning body such as this is a structure that must be established if public knowledge, attitudes, and practices are ever to grow and change. The services of state and local government have to be combined with private and voluntary agencies, community organizations, and schools for there to be comprehensive planning. The proposed task force is to consist of 23 members and be funded from a $75,000 appropriation to the Department of Health from the general fund.

An approach that combines prevention, comprehensive services to teenage parents and their infants, and cooperative activities among agencies has the best chance to delay childbearing among teenagers and provide the best services for school-age parents (Alan Guttmacher Institute 1981; McGee 1982; Dryfoos 1985; Women and Foundations 1985).

New Jersey Network on Adolescent Pregnancy

Second, as to *private initiatives*, community and public education are part of the broader whole program of prevention that needs to be designed. Public and community education need to be part of the outcome of evaluating programs that are in place and those that are being planned.

Cooperative activities have been organized since 1979 by the New Jersey Network on Adolescent Pregnancy, funded by private foundations. The network is located in the Center for Community Education of the School of Social Work of Rutgers, the State University.

"County Networks" of this organization coordinate the activities of 2,500 persons who represent 450 agencies and organizations around the state that are concerned about the issues. The network provides these services:

1. Retrieves and disseminates printed and audio-visual information through a clearinghouse

2. Publishes the quarterly newsletter, *Exchanges*, and publishes a resource directory of 600 pages, with separate county editions

3. Provides technical assistance and consultation to agencies and organizations as to research, program development, and avoiding duplication of services

4. Provides conferences and seminars and in-service training

5. Identifies public issues and policies as to gaps and duplications in services

6. Created a Northeast Regional Network on Adolescent Pregnancy and Parenting for 11 northeastern states around policy and program issues.

We recommend that funding be provided by the legislature for the New Jersey Network on Adolescent Pregnancy. The network should be maintained at the state university as both a "neutral place" in an educational setting and in a setting where direct support services are not provided.

Other states are supporting public-private networks such as these more effectively. New Jersey's network is one of four in the nation (North Carolina, Texas, Michigan, and New York City). State funding comes to the networks for all but New Jersey's. Among projects that they support are health care, use of peer educators, strategies for delivering services by neighborhoods, parent-child seminars, delivery of contraceptive services to adolescents, and program evaluation.

Tertiary Prevention: Comprehensive Services

Programs to encourage prenatal care in New Jersey languish for lack of funds. The council's staff surveyed a number of agencies and organizations, looking for model programs and innovative approache that ensure the best outcome among young women who are already pregant. A brief review of some of these programs gives an impression of what will need to be developed.

We found several programs that provide a similar education, health, and counseling services and require a staff ratio of about one staff person to four clients.

Costs for these comprehensive services average about $3,500 per client per year.

Without such programs, the costs of each pregnancy to society are probably much higher. By comparison, education costs average $10,000 per year. Medical expenses for birth and delivery, public assistance, medicaid, and food stamps for a teenager and her infant average $8,474 per year.

Camden and Hudson Counties

An alternative school, or family living center, can be provided by the school district to educate pregnant adolescents. The services of pediatric nurses, guidance counselors, social workers, and other specialists have to provided, along with infant care, transportation, food services, and other supports.

Costs for an in-school program such as this would be $100,000 for each 20 students, or about $5,000 per student.

Gloucester County

The Lighthouse Community is a program that accommodates 28 women aged 18-25 years with residential services. To encourage independent living skills, each mother and child has a private room and receives education and tutoring; adoption counseling; parenting skills; information on rehabilitation, job services, and family day care. These services are provided for a fee of $125 per month.

Staffed by volunteers, the program requires a residential facility, full-time administration, a counselor, a secretary, and house supervisor. Overall expenses have been about $100,000 per year. At the rate of serving about 1 in 10 persons who apply, costs average about $3,600 per client.

Essex County

AD House in Newark is a therapeutic center to help increase self-esteem, direction, and control and trust among pregnant adolescents. Participants are minority teens who need counseling in how to maintain a family unit; how to raise children; and how to finish school and find work. Some 20-25 adolescents are seen monthly, and 17 teenage mothers are served. The youngest participant is aged 10 years. The program helps overcome an adolescent's reluctance to go to school regularly and her risk of aggressive behavior because of deprivation of food, shelter, clothing, and discipline in the home. The costs of a program such as this are $3,400 per child.

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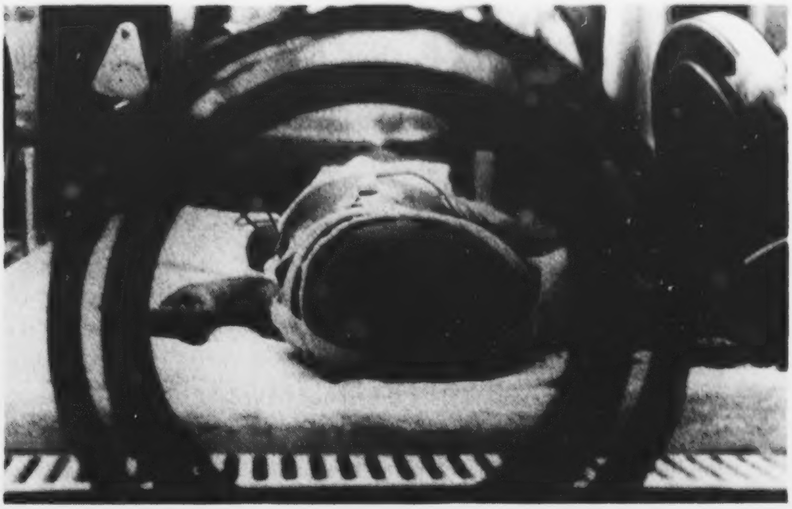

CHAPTER 12

INSURE THE MEDICALLY NEEDY

RECOMMENDATION

Mental retardation can result from lack of primary and preventive care, especially from lack of prenatal care and health care in early childhood. Poor people usually have neither a private family physician nor health insurance coverage.

Until 1985, New Jersey provided medicaid coverage only to the "categorically needy," that is, to those who are eligible for cash assistance. In 1985, however, legislation was enacted to extend medicaid coverage to the "medically needy." This would provide minimal health insurance to mothers and children who are not poor enough to qualify for public assistance; who do not have an employer-sponsored health plan; and whose income does not exceed 133 percent of the income limits for cash assistance.

This coverage would extend preventive health programs to a population of pregnant women and to infants and children who are most at risk of conditions that lead to mental retardation.

The council recommends prompt and comprehensive implementation of this important law, with effective outreach especially to those who are eligible for clinic care and to their infants. One-half the cost to the state of coverage is reimbursed by the federal government.

New Jersey, finally, should go beyond the categories defined by federal programs to reach all whose incomes leave women without health care coverage.

Employers and labor unions should be encouraged to support adequate coverage of employees and of their dependents.

A program and additional funds must be established to cover women who do not qualify for medicaid but who cannot afford health insurance or routine preventive health care. The program should be entirely state funded and should provide prenatal care, perinatal care, and services for the first four years of a child's life. Such a program can be administered under the medicaid system that is already in place, provided no claims for federal reimbursements are made to cover women and children who are not eligible for services under federal rules.

RATIONALE

Recipients, Services, and Funding under the "old" law

RECIPIENTS

Prior to the enactment of the program for the medically needy in New Jersey, medicaid was serving about 600,000 persons, annually. This included 483,000 recipients who are eligible because they receive Aid to Families with Dependent Children (AFDC) and/or are aged, blind, and disabled. In addition, about 12,000 clients in the Division of Youth and Family Services (including foster children, adopted children, and children in special residences); about 89,000 low-income, elderly or disabled clients on Social Security; and about 7,000 clients in state institutions for the mentally retarded and the emotionally disturbed were eligible for medicaid.

New Jersey now joins the majority (32) of states that cover people who are "medically needy." Under this program, people who have income above the new limit (133 percent of the AFDC standard) may be covered if they incur medical costs that reduce their net income and assets to the eligible levels. This "spend-down" provision can cover catastrophic situations.

SERVICES

Federal regulations now require in- and out-patient hospital care; laboratory and x-ray services; skilled nursing; early, periodic screening, diagnosis, and treatment; family planning; and physicians' services.

States may add other services. New Jersey provides more optional services than most states — only five states have a broader package. However, the fees that New Jersey allows for ambulatory care (not hospital or institutional care) are low compared to other states.

FUNDING

Thus, medicaid consists of programs that the state operates to cover costs of health care, "rehabilitation," and other specified services for eligible low-income residents of the state. The state pays the provider ("vendor"). In turn,

Table 12-1. — Numbers and percentages of funds for medicaid, by source of funds, for New Jersey.

Source of funds	Dollars	
	Thousands	Percentage
Total	**1,087,049**	**100.00**
Federal	460,548	42.37
State general funds		
Payments for medical services	464,309	42.71
Administration	56,390	5.18
State Casino Revenue funds	105,802	9.73

SOURCE: New Jersey Department of Human Services 1984 the state collects partial reimbursements from the United States Health Care Financing Administration.

Table 12-1 shows the sources of medicaid reimbursements for 1984. In general, the federal government reimburses New Jersey for about one-half the amount that the state spends each year on eligible direct-service costs for medicaid-eligible children and adults. Casino revenues are applied to the state share, but only for persons who are aged over 65 years or who are disabled.

The "New" Law

The new program will cover about 250,000 New Jersey citizens who have incomes below the federal poverty guidelines but who are not eligible for medicaid under the old law. To be eligible for medicaid prior to 1985, a family with children had to be $3,000-$11,000 *poorer* than the federal poverty guidelines, depending on the size of the family (Geismar and Schwarcz 1984). Those whose income is still below poverty, but who did not qualify for medicaid, are estimated to number 250,000 in New Jersey, including pregnant women and children, as shown in the accompanying tabulation *(Ibid.)*.

Total	**255,000**
Children	100,000
Elderly	90,000
Working poor	50,000
Blind, disabled	12,000
Pregnant women	3,000

Everyone in this group is more likely to have illness than is the more affluent general population. Further, the children, pregnant women, and working poor in this group, who number 153,000, include many who are most at risk of mental retardation and who can benefit most from preventive health services.

For instance, it is especially important that "caretaker relatives" be provided with services. "Caretaker relative" is a euphemism that includes *single mothers, grandparents, aunts, siblings*, and so on. These single parents are most likely to be adolescent mothers, or to be caring for the children of adolescent mothers, and to have very little health care. Therefore, their children are at *highest risk of mental retardation*. Coverage will protect the mother, the child if the mother is ill, other children, and the proper functioning of the family.

Reimbursement Rates Are So Low, Not Enough Services Are Available

Extending coverage is important but will be effective only if eligible persons can actually get services from the agencies and practitioners to whom they have access.

The rates at which physicians and other providers may be reimbursed by medicaid are so low that not enough providers can be found who will accept medicaid clients. As the New Jersey Commission on Children's Services (1982) reported:

> Although Medicaid is supposed to assure that impoverished children receive health care services, many providers will no longer accept Medicaid patients, since the reimbursement rates for ambulatory care do not cover the actual cost of providing care. For example, at one Camden facility where a visit costs $25, Medicaid will pay only $9 for the visit. As a result of this disparity between the cost of care and the Medicaid rates of reimbursement, it is becoming increasingly difficult for Medicaid patients to obtain preventive care services.

Costs Escalate Naturally

Yet, even if few are enrolled and reimbursement rates are low, the costs of medicaid grow at an alarming rate. The National Governors' Association (1984) reports that "Medicaid is the largest state administered program in state budgets and, along with other health care financing programs, the most rapidly escalating cost."

In New Jersey, according to the Governor's Management Improvement Team, medicaid expenditures have been increasing at about 14 percent per year, in contrast to the average annual increase of only 10 percent in the state's resources.

Governor Kean put this in the national context in 1984:

> Health care is the single most inflationary factor in the American economy today. Last year the cost of medical care rose about 12.5 percent, twice the increase in the consumer price index. The total bill came to $321 billion. That's a levy of almost $1,400 on every man, woman, and child in the country. That bill is expected to rise to $675

> billion by 1990....While general expenditures increased 12.7 percent from 1981 to 1983, state medicaid spending increased almost 21 percent (Kean 1984).

PREVENTION PROGRAMS SHOULD REDUCE THE NEED FOR INSTITUTIONAL CARE

Our chapter, "The Scope of Mental Retardation," shows the costs of mental retardation in New Jersey in public tax dollars, including the nearly $300 million for institutional care, which is paid, in large part, by medicaid.

If we provided better health care for our citizens when they are young, we would probably have less institutionalization. We recommend one approach to providing better services and controlling costs: emphasize prevention programs for the medically needy. The more preventive health care reduces the prevalence and severity of mental retardation, the less the need there may be for expensive institutional care in the future for people with mental retardation and related disabilities.

Prenatal, Maternity, and Infant Care

In the first prenatal visit, most of the health risks that are associated with low birth weight can be evaluated (United States Department of Health and Human Services 1980). While women who have no prenatal care bear their infants prematurely in 28 percent of cases, women who have prenatal care bear their children prematurely in only 5 percent of cases (Bondy 1983). When maternity services were provided 7,000 low-income women over 3 years in California, rates of low birthweight were 50 percent below those of comparable women who did not participate in the project (State of California 1982). Prenatal care has been found to reduce neonatal and infant mortality by 60 percent in Cleveland (Lazarus 1983), by 50 percent in California (Norris and Williams n. d.), and by 20 percent in New York City (Kressner 1974).

A Michigan report determined that to provide prenatal care to 14,000 women would save about $6.12 for each $1 spent (Michigan Department of Public Health 1983). Drawing on many similar studies, Weitz and Rosenbaum (1984) determine that prenatal and maternity care saves $4-$9 in maternity and infant costs for every $1 spent.

Many of these same data show extensive cost-benefits for perinatal and infant care, too. In California, the costs for enrolling 1,000 women in a perinatal programs for 5 years were $750,000. A comparable group who did not receive these services cost $4.6 million (Weitz and Rosenbaum 1984).

In general, as the Association for Children of New Jersey has pointed out, the costs of medicaid are dramatically lower than the medical costs that are borne when women do not have prenatal care and when children do not have health care as they grow. Prenatal care, including delivery, costs Medicaid $1,400; but hospital care for a child born sickly as a result of lack of prenatal care cost $1,000 per day, for an average of 20 days. Immunization and checkups for a child cost $600, but hospitalization for diphtheria or measles costs Medicaid thousands (Geismar and Schwarcz 1984).

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CHAPTER 13

ENSURE FULL-TERM BIRTHS

RECOMMENDATION

Premature infants make up a disproportionate share of the mentally retarded. Most preterm infants are low in weight, and very-low-birth-weight infants have a high risk of impairment. The President's Committee on Mental Retardation has stated that "the premature, low-birth-weight baby has about a 15 times higher risk of retardation than the normal infant..." (1980).

Every year, over 1,000 infants are born prematurely in New Jersey with a birth weight under 1,500 grams. A high percentage of these children will be mentally retarded, have a minor impairment, or have a learning disability. Given proper prenatal care, many of these children could have been carried

to full term. Such a program reported cost savings in just lower physicans' fees and hospital fees for neonatal intensive care to be $11,240 per birth in 1984, for a full-term birth, versus a premature, very-low-weight birth.

Programs should be established in level III perinatal centers in New Jersey hospitals to prevent preterm births by

1. **Identifying patients at risk of preterm birth**
2. **Educating patients in the signs of preterm labor**
3. **Educating obstetric staff**
4. **Providing weekly follow-up**
5. **Providing outreach programs to school nurses**

These hospital programs should have special components to reach poor, inner-city women through community-based agencies such as schools and churches.

Funds (to supplement medicaid and other third-party payments) should be provided for prenatal care in level III centers and for the "uniform perinatal record" to be maintained by the Medical Society of New Jersey.

RATIONALE

Preterm Births Risk Mental Retardation

Studies have shown that preterm infants, especially those born at very low birth weight, have a high risk of severe impairment: mental retardation and

Table 13-1. — Numbers and percentages of resident live births which were very low birth weight (1500 grams) or low birth weight (2500 grams), for New Jersey, 1979-1983

Year	Total	Live births			
		Less than or equal to 1,500 grams		Less than or equal to 2,500 grams	
		Number	Percentage	Number	Percentage
1979	95,661	1,176	1.23	6,854	7.16
1980	96,410	1,147	1.19	6,884	7.14
1981	96,127	1,148	1.19	6,745	7.02
1982	98,225	1,163	1.18	6,700	6.82
1983	98,746	1,205	1.22	6,975	7.06

SOURCE: New Jersey Department of Health 1984

related disorders (Nelson and Broman 1977; Commey and Fitzhardinge 1979; Shapiro *et al.* 1980).

In New Jersey, each year, approximately 40 very-low-birth-weight infants and 170 low-birth-weight infants can be expected to have a major handicap, such as cerebral palsy, IQ below 70, severe hearing or vision loss, and other disabilities (Kern 1984). Low birth weight occurs in about seven percent of live births, as shown in Table 13-1. Numbers of children who were affected in New Jersey counties in 1980 are shown in Table 13-2.

Table 13-2. — Numbers and percentages of total births and births under 2,500 grams, by county, for New Jersey, 1979

County	Total births		Birthweight under 2,500 grams	
	Number	Percentage	Number	Percentage
Total	**95,672**	**100.00**	**6,854**	**100.00**
Atlantic	2,561	2.68	176	2.57
Bergen	8,369	8.75	438	6.39
Burlington	4,260	4.45	246	3.59
Camden	7,214	7.54	544	7.93
Cape May	1,012	1.05	66	0.96
Cumberland	1,991	2.08	136	1.98
Essex	11,952	12.49	1,186	17.30
Gloucester	2,946	3.08	189	2.76
Hudson	8,218	8.59	714	10.42
Hunterdon	1,102	1.15	36	0.53
Mercer	4,159	4.34	361	5.27
Middlesex	7,153	7.48	500	7.30
Monmouth	6,075	6.34	412	6.01
Morris	4,866	5.08	274	4.00
Ocean	4,635	4.84	270	3.94
Passaic	6,547	6.84	547	7.98
Salem	976	1.02	66	0.96
Somerset	2,237	2.34	119	1.74
Sussex	1,868	1.95	90	1.31
Union	5,874	6.14	393	5.73
Warren	1,090	1.14	63	0.92
State institutions	5	0.00	0	0.00
Military	562	0.59	28	0.40

SOURCE: New Jersey Department of Health n.d.1

The data in Table 13-1 suggest that low birth weight is a persistent problem, which has not lessened in recent years. Moreover, low birth weight is more common among minority, low-income women, as shown in Table 13-3.

Table 13-3. — Numbers and percentages of low birth weights, by race of mother, for New Jersey, 1982

Race	Total births	Birthweight (grams)			
		2,001-2,500	1,501-2,000	1,001-1,500	1,000 or less
Total	**98,225**	**4,233**	**1,304**	**581**	**582**
White	75,737	2,652	763	317	339
Black	18,661	1,470	509	256	233
Other	2,102	106	31	5	8
Unknown	1,725	5	1	3	2
Total	**100.00**	**4.30**	**1.33**	**0.59**	**0.59**
White	100.00	3.50	1.00	0.42	0.45
Black	100.00	7.88	2.73	1.37	1.25
Other	100.00	5.04	1.47	0.24	0.38
Unknown	100.00	0.29	0.06	0.17	0.12

SOURCE: New Jersey Department of Health n.d.2

Black infants are about twice as likely as white infants to have low birth weight (Weitz 1983). The Children's Defense Fund has presented evidence that this is owing to the fact that low-income women have no, or inadequate, insurance and access to prenatal care. So, they are 50 percent less likely to receive prenatal care in the first trimester.

Table 13-4. — Percentages of adequate and inadequate prenatal care, by race and birth weight of infants, for New Jersey, 1983

Infants	Percentage of prenatal care that is:	
	Adequate	Inadequate
Race		
White	72	22
Black	45	45
Low birth weight	6	11

SOURCE: Meltzer 1985

This turns out to be so in New Jersey, as Table 13-4 shows. Black mothers are about twice as likely not to have had prenatal care; and infants who have had inadequate prenatal care are about twice as likely to be born under weight.

The problem is compounded by the numbers of births to adolescents and teenagers. They accounted for about 11 percent of births in New Jersey during the years 1979-1981, but who accounted for about 17 percent of the infants who died before their first birthday (Associated Press 1984). (See our recommendation, "Reduce the Risk of Adolescent Pregnancy.")

Patient and Professional Education Can Prevent Preterm Births

REACHING WOMEN THROUGH HOSPITALS

One of the ways to increase birth weights is to increase the length of gestation among women who risk preterm birth. An example of such a program is that developed by Robert K. Creasy (*et al.* 1980) which makes it possible to determine which pregnant patients are at high risk of preterm delivery.

This program produces very favorable results in the form of an exceptionally low rate of prematurity (Herron, Katz and Creasy 1982).

1. Patients who are registered to deliver at a hospital or clinic are scored on their socioeconomic status, past reproductive history, and current pregnancy.

2. Women in the program are taught signs and symptoms of preterm labor with intensive education given to those women determined to be at risk for preterm delivery.

3. Those at high risk are trained in stress management, in increasing rest periods, and in refraining from breast preparation until the 37th week of pregnancy; and are followed weekly.

4. Physicians, nurses, and other health personnel are trained to recognize patients' risk characteristics and to intervene appropriately if premature labor occurs.

5. Where indicated, "tocolytes," medications that increase the time of gestation by many weeks, are prescribed and their use is monitored.

It already has been shown that it is cost beneficial to arrest preterm labor *just with medication.* Increased costs of prenatal care are offset by the decreased costs of neonatal care. For instance, perinatal data on 411 patients at the University of California Hospital were reviewed for 1978-1982 for the costs of arresting preterm labor with tocolytic therapy. Delaying birth results in lower physicians' and hospital's fees, including those for neonatal intensive care where preterm birth occurs. In the California study, there were expected savings of $11,240 per birth (Korenbrot, Aalto, and Laros 1984).

Programs on the "Creasy" model are more cost-effective because they make medication more effective. Tocolytic agents may fail to decrease the number of preterm deliveries, unless the signs of preterm labor are recognized early enough. Educating patients and professionals about these signs enables the use of tocolytic agents to decrease the number of preterm births significantly (Herron, Katz, and Creasy 1982). For Creasy's program, 33 percent, 50 percent, and 70 percent decreases in prematurity have been reported.

A PILOT PROJECT IN NEW JERSEY

A model for the prevention of preterm births has been in operation for the past year at University of Medicine and Dentistry of New Jersey — Rutgers Medical School and St. Peter's Medical Center. The project is funded by the Hunterdon Health Fund and the National March of Dimes Birth Defects Foundation.

The project is designed around the Creasy model and includes six counties around the perinatal center. To date, 24 obstetricians and 10 hospitals have joined the project.

The original Creasy program showed a 50 percent reduction in premature births in a "closed" system (that is, among patients managed by the perinatal center). In a closed system, the premature delivery rate among patients who participate in the prevention protocol is less than one percent. However, when the system is "opened" to include patients who come to physicians' offices, participation and uniformity lag, and the experience is that the reduction in preterm delivery will have to be built up, probably over a five-year period. It is estimated that a 10-20 percent reduction will take place the first year with a goal of 50 percent in five years.

The costs of the project are well below the cost of care for one infant under 1,000 grams for two infants below 1,500 grams, as shown in the accompanying tabulation of the costs of the project for the first year. (This includes additional costs incurred by the medical school and by the medical center as their contribution to the project.)

ITEM	DOLLARS
Total	**$43,000**
Nurse clinical specialist (bachelor's degree)	26,000
Secretary (20 hours)	8,000
Telephone (1-800-545-BABY)	2,000
Materials and supplies	3,000
Transportation (per call to hospital and doctor's offices)	1,000
Consulting fees for nutritionist and other consultants	4,000

REACHING SPECIAL GROUPS OF WOMEN

Not all pregnant women seek prenatal care through out- patient clinics or through private physicians, especially poor women in the cities. So, any network of prevention programs would have to have special components that reach out to these women who are at highest risk.

Risk assessment models for preterm birth prevention can be refined according to the target population and not be confined to hospitals and their community-education programs. Low-income women in the inner city may lack motivation for participation in risk assessment programs. They may experience problems such as difficulty in getting to health care facilities for risk assessment or for management of preterm labor because of lack of transportation or responsibility for other children.

To address the special needs of low-income women, a different strategy can be devised. Education of community groups about the importance of risk assessment in the prevention of preterm labor would be central. Peers can be trained to motivate women to participate. Moreover, support groups can help in the successful management of high-risk pregnancies among inner city women. Peer- and support groups can involve churches and other community organizations (Harrigan 1985).

New Jersey Has the Resources for Education on the Creasy Model

The resources for the proper combination of hospital and community education and outreach already exist in New Jersey. Since 96 percent of live births in 1978 in New Jersey took place in hospitals (New Jersey Department of Health 1982), the hospital is the premier place where expectant women can be reached. Needed outreach to special groups of women can be carried on through the special consortia that hospitals have with other community agencies through cooperative agreements.

A PROGRAM FOR PREVENTING PRETERM BIRTHS IN SOUTHERN NEW JERSEY

An example of a cooperative agreement among hospitals is the Southern New Jersey Perinatal Cooperative, a consortium of all 15 hospitals in seven counties that is funded by a small fee collected for each live birth and by private fund-raising. This consortium provides for a board, on which hospitals and consumers have representatives.

In a consortium, a program to prevent preterm births based on the Creasy model would not be expensive or complicated. The task force learned that such a program would require a full-time nurse to act as educator and coordinator, a half-time secretary, a telephone and "hotline," and some materials and supplies for educating physicians and patients. Total costs are shown in the accompanying tabulation.

PREVENTION OF PRETERM BIRTHS FOR ONE YEAR	**DOLLARS**
Total	**50,000**
Direct costs	39,500
Nurse (full-time)	27,500
Secretary (half-time)	6,500
Telephone and "hotline"	1,800
Materials and supplies	3,700
Indirect costs	10,500

The Southern New Jersey Perinatal Cooperative estimates that *just* providing consultations to professionals will save $787,000 in net payments avoided by third-party payers in 1984 (Smull 1984).

PROGRAMS FOR PREVENTION OF PRETERM BIRTHS IN OTHER HOSPITALS

Other regions of the state are served by hospitals that have been designated "level III perinatal centers" by the New Jersey Department of Health. These centers can provide for complicated maternity and newborn patients; for birth complications; and for extremely complicated fetal, neonatal, and maternal cases. The state is divided into regions by the federal system of "health systems agencies," and these level III centers have been designated for the regions:

LEVEL III PERINATAL CENTER	HEALTH SYSTEMS AGENCY REGION COVERED
Beth Israel Newark	Region I
Cooper Medical Center/ Our Lady of Lourdes Camden	Region V
Monmouth Medical Center/ Jersey Shore Medical Center Long Branch/Neptune	Region IV
St. Joseph's Medical Center Paterson	Region I
St. Peter's Medical Center New Brunswick	Region IV
Statewide Perinatal Center (College/United Hospitals) Newark	Region II

Cost Estimate

FOR PROGRAMS IN PERINATAL CENTERS

A program to prevent preterm births for each of these centers might require 10 percent of a physician's time, a full-time nurse, and equipment and supplies.

A basic program for each center would cost about $70,000 per year, and costs should go down once the "start-up" expenditure is made. If each level III center were to have a program, the cost would be about $400,000 for all.

In sum, we recommend that programs to reduce the incidence of preterm births based on the Creasy model and on other models be initiated in the six level-III perinatal centers because the programs are an effective preventive mechanism.

FOR THE UNIFORM PERINATAL RECORD

Support of the "uniform perinatal record" will be needed. This record system, now nearly developed, will enable obstetricians and pediatricians to identify, track, and manage high risk pregnant women and their newborns better. It is planned that a central statewide office be established to manage the use of the record and to compile perinatal data. This office would be established under the auspices of the Medical Society of New Jersey at a projected cost of $70,000. The cost for preterm birth prevention would be $270,000.

The Robert Woods Johnson Foundation reports that a "neonatal intensive care unit costs about $1.5 million to build and equip, $2.6 million to operate annually, and its cost per patient per day is $500" (New Jersey Department of Health 1982). We do not have average *per-person* costs of preventing preterm births, but a program cost of $70,000 per center is surely much lower.

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CHAPTER 14

FOLLOW UP INFANTS WITH BIRTH DEFECTS

RECOMMENDATION

Many congenital malformations (birth defects) are likely to be associated with mental retardation, if the infant survives. Congenital malformations are a serious health problem in New Jersey. In New Jersey, 2,000-3,000 infants *each year* could be expected to be born with a serious malformation.

Registering children with birth defects makes it possible to follow up on treatment and provide services that might not otherwise be available. Appropriate and prompt medical treatment can reduce the extent of complications, long-term illness, disability, and death. But physicians, health professionals, and parents do not always know what interventions are appropriate, where services can be obtained, and how problems such as costs

can be resolved. In order to make prompt answers to their questions available, and to assure continuity and coordination of care, as infants grow up, the New Jersey Department of Health is required to maintain a registry of birth defects and to provide case management to assist physicians and families. But this system is relatively new and has not been fully implemented because the state has not provided sufficient funds.

An integrated system for tracking and evaluating infants and children identified as being at risk for mental retardation should be fully imlemented by the New Jersey Department of Health. The system should:

1. **Provide for early identification and referral of those children who show evidence of developmental delay**
2. **Confirm suspected causes retrospectively for inborn errors of metabolism, lead poisoning, and other high-risk conditions.**

The department has already taken great caution and care to plan for a system that provides confidentiality and avoids premature labeling or categorizing of a population that is at risk. It is therefore recommended that the tracking system be extended to those children with diseases, disorders, conditions, or documented exposures for which there is strong medical evidence of risk for mental retardation.

> **An appropriation of $580,000 is needed to put in place and maintain an integrated tracking system for children who may be at risk for mental retardation and developmental delay.**

RATIONALE

Services to Children with Birth Defects

The Department of Health supports a variety of programs that identify children who may be at risk for developmental delay or other related disabilities, but an integrated system for tracking these children has not been fully developed. The nucleus of such a system exists in its Division of Local and Community Health Services, which already has responsibility screening for inborn errors of metabolism, screening for birth defects, detecting lead poisoning in children, and following up infants subject to high-risk conditions.

SPECIAL CHILD HEALTH SERVICES

The legislature directed the New Jersey Department of Health to set up a birth defects registry in 1983 (P. L. 1983, Ch. 291). *Confidential* records of all birth defects to children born, and defects of all naturally and electively aborted fetuses after 15 weeks of gestation are supposed to be kept. The Commissioner of Health is empowered to determine what health care facilities should provide this information and the extent of the information to be provided. The registry cannot report anyone's identity, and no one can be compelled to submit to a medical examination or to be supervised by the department, according to the law.

No funding was provided by the legislature to implement this act. The department does as much registration as it can with funds taken from the federal maternal and child health block grant, but these funds are not sufficient, and the department is already committed by law to other programs. *As a result, registration is incomplete, and not enough follow-up is possible.*

Fewer infants are registered with Special Child Health Services than are born with malformations, because the registration system needs additional resources. It is not quite certain exactly how many infants are born with serious malformations in New Jersey. While as many as 3,000 may be born at risk, in 1983, 1,734 infants were *registered* with Special Child Health Services in the New Jersey Department of Health as having birth defects. Among these infants, 177 can be expected to be mentally retarded, 45 have neural tube defects, 21 have microencephaly, and 101 have chromosomal abnormalities.

INBORN ERRORS OF METABOLISM

Some 45 states now have laws that require the screening of newborns for genetic and chromosomal conditions of mental retardation, so-called inborn errors of metabolism. New Jersey screens for three conditions — phenylketonuria, hypothyroidism, and galactosemia.

The number of infants expected to be born in New Jersey each year with inborn errors of metabolism and related conditions is shown in Table 14-1.

Table 14-1. — Expected numbers of cases of inborn errors of metabolism and of related conditions, for New Jersey, 1984

Condition	Expected numbers of cases per year in New Jersey*
Phenylketonuria	6-9
Hypothyroidism	16-20
Galactosemia	0-2
Homocystinuria	0.50
Maple syrup urine disease	0.50
Sickle cell anemia	0.50
Tyrosinemia	N.A.
Tuberous sclerosis	N.A.
Histidinemia/adenosine deaminase deficiency	3-4

SOURCE: New Jersey Department of Health 1984

*Based on 100,000 live births per year

N.A. means not ascertained.

Virtually all newborns in the state are tested for the first three conditions listed in Table 14-1. A sample of the infant's blood is placed on a filter paper form and sent to the central inborn error of metabolism laboratory located in the Department of Health in Trenton. A charge of $4 is made for the initial test, the cost is usually incorporated into the bill for the hospital stay for delivery, and there is no charge for repeat tests.

All abnormal results are followed up through a program based in the department's Special Child Health Services. In cases of presumptive positive test results, the follow-up program immediately notifies the child's health care provider so that a confirmatory specimen can be obtained and treatment started. All cases of abnormal results are followed until the presence of abnormality is either confirmed or ruled out.

Table 14-2 lists confirmed positive cases identified through New Jersey's program for screening for inborn errors of metabolism and for related conditions. Had these children been identified after the clinical presentation of symptoms, and been only moderately retarded, special education costs alone for each child would have totaled at least $100,000. If the children were severely handicapped, requiring institutionalization, the costs would be much higher — $40,000 per year for each child.

Table 14-2. — Numbers of abnormalities detected by newborn screening of live births, by year, for New Jersey, 1979-1983

Year	Live births	Abnormalities detected		
		Phenylketonuria	Hypothyroidism	Galactosemia
1979	95,672	6	19	N.A.
1980	96,438	9	17	N.A.
1981	96,127	3	15	N.A.
1982	98,225	7	22	0
1983	98,746	6	23	3

SOURCE: New Jersey Department of Health 1984

N.A. means not ascertained.

LEAD POISONING

According to the Governor's Committee on Children's Services Planning, at least 220,000 preschool children in New Jersey living in areas of the state that are at are at high risk for lead poisoning, a preventable cause of mental retardation and of other learning disabilities (Andersen and Mayer 1984). The existing screening programs funded by the New Jersey Department of Health with federal money *reached only about 23 percent of these children who live in high-risk areas.* (See our recommendation, "Test Every Child in High-Areas for Lead Poisoning and Abate the Hazards of Lead.")

When children are identified as having high blood-lead levels, medical treatment must begin to avoid damage to the brain. Inclusion of lead poisoned children in a registry would permit follow-up contacts with parents to ensure proper treatment.

Integrated System Needed

An integrated system is needed for tracking and evaluating children who may be at risk for mental retardation and developmental disabilities. This could be accomplished through the network of child evaluation centers currently supported by the Special Child Health Services Program. Additional funding will allow these centers to carry out the evaluations through standardized protocols.

The role of the parent in tracking is key to the success of any registry. Parents should be fully informed why their child is at risk, what "at risk" means, and about the importance of maintaining contact with the Department of Health on a regularly scheduled basis. The role of the parent will be complemented by the Special Child Health Services case manager in the parents' county of residence. When an infant or child is identified as at risk, the case manager will be notified and informed of the schedule for contacts and evaluations. The feasibility of developing and distributing personal health profile records to these parents should be explored.

The case manager supplements the primary role of the physician and assists in mobilizing social and educational resources as well as the needed services.

In addition to providing support for tracking through existing case management units, periodic monitoring of infants who meet certain criteria will be provided through home visits by public health nurses.

Standardized schedules for monitoring contacts and referrals of evaluations will be developed according to the child's age and risk factors. For example, tracking of females with phenylketonuria (PKU) will extend into childbearing age while tracking for children treated for lead poisoning will be discontinued at an earlier age.

OTHER USES FOR A REGISTRY

Information

A registry, along the way, can contribute to basic epidemiology and to measuring the impact of health care on the residents of the state. This would fill gaps in our information about the extent of mental retardation.

Over and over, council staff have found that information on the incidence and rates of various conditions simply is not available. The Centers for Disease Control in Atlanta confirm the suspicion that there simply is no epidemiology of mental retardation (Berry 1984). A registry that is implemented with appropriate comprehensive features can begin to provide the unique service of correct epidemiology for the citizens of the state.

EVALUATION

A registry, too, can make it possible to measure the impact of health care on the citizens of the state. It is almost as common not to know what health care programs are effective as it is not to know how many people have a particular health problem. Since the principle of a registry is to see that treatment is provided, a registry can serve to monitor access to, and the effectiveness of, treatment programs.

PLANNING

Finally, a registry will make it possible to assess new risks of mental retardation as these develop in the coming years. For instance, environmental contaminants are likely to prove even more important in coming years. (See our recommendation, "Develop Information on Exposure to Environmental Contaminants.")

A registry will permit studying both short- and long-term effects of teratogens and mutagens. This will make it possible to develop base-line data so that data on future incidence can be compared in a useful fashion. In this way, needs for genetic services and other forms of health care can be identified and descriptive studies can be planned with less guesswork.

COST ESTIMATE

New Jersey should appropriate $580,000 in fiscal year 1987 to establish and maintain an integrated tracking system for children identified as born under conditions that put them at risk for mental retardation and developmental delay. (This is in addition to the funds requested in our recommendation, "Follow Up Infants at High Risk.")

The Department of Health estimates the costs of carrying out the recommendations for as follows:

PROGRAMS	DOLLARS
Total	**$580,000**
Additional staff for births defects registry	80,000
Additional case management staff	300,000
Additional resources for child evaluation centers	200,000

Registry

The registry staff would be expanded by two professionals who would (1) provide the necessary coordination of such a statewide effort within the case management system and (2) collect and analyze the follow-up information to determine the effectiveness and benefits of such a follow-up process.

Case Management

Additional resources would be needed primarily within the case management system (including public health nursing visits as needed), since this service is not covered by health insurance. The existing case management system and its use of public health nursing services would have to be expanded to provide continued contact with children being followed. The additional services would require some of the counties covered by part-time case managers to have full-time coverage.

Child Evaluation Centers

The needs for additional resources in the child evaluation centers would not be so great as expected since medicaid and other health insurance coverage would cover costs for children insured by these programs. Funds would be available to five of the Child Evaluation Centers on a regional basis to provide for these expanded evaluations. One requirement of these five centers would be the ability to integrate genetic services into these evaluations. (Halpin 1985)

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CHAPTER 15

FOLLOW UP INFANTS AT HIGH RISK

RECOMMENDATION

Because of the unfolding of the organism and the influence of the environment, conditions that lead to mental retardation may not show up immediately upon birth, but may appear later in life. Infants who are premature or who display certain conditions at birth are classified as "high-risk" infants because they continue to be at risk for years after birth, even though there may be no visible congenital anomaly.

A comprehensive program should be developed to follow up infants who are at high risk of mental retardation. This program should build on the network of programs in level III newborn care facilities and should include:

1. Increasing the number of infants who now receive follow-up services by including high-risk infants born in or transferred to level III and level II facilities

2. Adopting a common protocol for assessing high- risk infants

3. Developing a data base to evalute the effects of specific forms of therapy and management during the perinatal period

4. Establishing a system to coordinate services provided to high-risk children to ensure continuity of care

To provide follow-up for all the children who are at risk would require an annual budget increase of $510,000 (in addition to the current allocation of $390,000).

RATIONALE

Handicapping Conditions May Not Show Up at Birth

Conditions that may result in mental retardation may not be apparent at birth. In this regard, the first four years are crucial. For example, children with cerebral palsy often appear normal until age six months, at which point they are discovered to be unable to sit up (Lewis and Fox 1983). Such children are likely to show evidence of some degree of retardation later on, although this is by no means inevitable.

High-Risk Infants

Infants who weigh less than 1,500 grams at birth or who exhibit signs of perinatal asphyxia, neonatal seizures, sepsis, or withdrawal from narcotics are known to be at high risk for mental retardation and delayed development. The numbers of children who were affected with each condition in 1983 are shown in Table 15-1.

Table 15-1. — Numbers and percentages of infants affected by conditions that result in a high risk of mental retardation and delayed development, for New Jersey, 1983

High-risk conditions	Infants	
	Number affected*	Percentage of all births
Total	**5,831**	**5.90**
Required assisted ventilation	3,863	3.91
Weighed less than 1,500 grams at birth	1,314	1.33
Sepsis	414	0.42
Seizures	240	0.24

SOURCE: Kern 1984

* The high-risk conditions are not mutually exclusive, so that an infant may be counted in more than one category.

Most High-Risk Infants are Never Followed Up

New Jersey has begun programs to follow up these infants who are at high risk. In such programs, hospital personnel identify children who are at high risk, visit them regularly, and screen them by examination. Such programs require the services of a physician who acts as coordinator, a nurse, a social worker, a psychologist, and a clerk. During the year 1979-1980, the Special Child Health Services Program of the New Jersey Department of Health funded one high-risk infant follow-up program at Monmouth Medical Center. In 1981, funding was extended to all nine hospitals that participate in the department-certified "level III perinatal centers."

The numbers of children who were registered for follow-up through these centers in 1983 are shown in Table 15-2.

Table 15-2. — Numbers of children at high risk of chronic disease and other handicapping conditions who were followed up in the High-Risk Infant Follow-up program of the New Jersey Department of Health, by hospital and county, for New Jersey, 1983

County	Hospital									
	Total	(a) SJ	(b) UCH	(c) UNV	(d) OLL	(e) CMC	(f) NBI	(g) MMC	(h) JSM	(i) SPM
Total	**2,969**	**451**	**710**	**495**	**121**	**117**	**429**	**219**	**244**	**3 183**
Out of state										
Pennsylvania	7	4	0	0	0	0	1	1	0	1
New York	7	6	0	0	0	0	1	0	0	0
New Jersey										
Atlantic	5	0	0	0	0	5	0	0	0	0
Bergen	128	97	26	0	0	0	4	0	0	1
Burlington	50	0	0	0	25	24	0	0	1	0
Camden	129	0	0	0	54	73	0	2	0	0
Cape May	6	0	0	0	3	3	0	0	0	0
Cumberland	24	0	1	0	18	5	0	0	0	0
Essex	1,114	4	380	494	0	0	236	0	0	0
Gloucester	23	0	0	0	17	6	0	0	0	0
Hudson	137	20	114	0	0	0	3	0	0	0
Hunterdon	12	0	3	0	0	0	2	2	0	5

Table 15-2, continued.

County	Hospital									
	Total	(a) SJ	(b) UCH	(c) UNV	(d) OLL	(e) CMC	(f) NBI	(g) MMC	(h) JSM	(i) SPM
Mercer	26	0	0	0	0	0	0	7	2	17
Middlesex	178	0	25	1	0	0	41	5	1	105
Monmouth ...	226	0	5	0	0	0	5	126	90	0
Morris	115	65	28	0	0	0	17	4	0	1
Ocean	225	1	5	0	0	0	0	69	150	0
Passaic	236	216	8	0	0	0	12	0	0	0
Salem	5	0	0	0	4	1	0	0	0	0
Somerset	51	1	5	0	0	0	5	1	0	39
Sussex	41	27	14	0	0	0	0	0	0	0
Union	194	2	76	0	0	0	102	1	0	13
Warren	30	8	20	0	0	0	0	1	0	1

SOURCE: New Jersey Department of Health 1984

(a) SJ is St. Joseph's Hospital
(b) UCH is United/College Hospital of New Jersey
(c) UNV is University Hospital
(d) OLL is Our Lady of Lourdes
(e) CMC is Cooper Medical Center
(f) NBI is Newark Beth Israel Medical Center
(g) MMC is Monmouth Medical Center
(h) JSM is Jersey Shore Medical Center
(i) SPM is St. Peter's Medical Center

Many children who are born under the conditions of a high risk of mental retardation and developmental delay (Table 15-2) still are *never followed up after they leave the nursery,* however. In 1983, 5,817 newborns were identified with high-risk conditions. Overall about 30 percent of these infants can be followed up over a three- year period, given the limited resources of the Special Child Health Services Program.

When children are followed up, about 8 percent have medical problems after they leave the hospital of birth. The accompanying tabulation shows that among children aged 0-4 years who were followed up in 1983, chronic diseases or other handicapping conditions were found in 235.

CONDITION	NUMBER OF CASES, 1983
Total	235
Developmental delay	153
Neurological problems	72
Cerebral palsy	3
Orthopedic problems	3
Infections (acquired)	1
Congenital anomalies	1
Hematologic problems	1
Problems of postnatal infection	1

SOURCE: New Jersey Department of Health 1984

It seems reasonable to assume that the children who were not enrolled in the High-Risk Infant Follow-up program for 1983 would be at risk of chronic disease or handicapping conditions at the same rate as those who were enrolled.

Increase Numbers in Follow-up Programs

Experience shows that early identification of chronic diseases and other handicapping conditions reduces the number of children who require specialized services at higher costs later in life.

Services

The services provided by the High-Risk Infant Follow-up program differ from regular pediatric visits. The follow-up program includes physical examinations, intellectual and emotional assessments, social work assessment and counseling for the family, and information and referral services.

PROGRAM FOR FOLLOW-UP

A complete follow-up program would require two major components: (l) program guidelines, including a common protocol for assessing infants at risk and a uniform data base to evaluate different forms of therapy and management during the perinatal period; and (2) support for additional services in the level III perinatal centers and hospitals.

Guidelines

The Department of Health should consult with the directors of the level III perinatal centers (and with such staff as the directors deem necessary) in the development of guidelines for high-risk infant follow-up programs. A uniform protocol should be designed by the department in consultation with the directors of the perinatal centers and their staff. One of the objectives of developing this expanded program would be increasing the range of data that can be collected. The age to which children are followed is recommended to be between five and eight years.

Services in Perinatal Centers

A multidisciplinary staff is required for a successful follow-up program. Likely to be included among such staff are a pediatrician or neonatologist to act as program coordinator, a pediatric nurse to conduct assessments, and a social worker who can assess features of the family system that may contribute to chronic diseases or other handicapping conditions.

Other specialists, such as psychologists and opthamologists, to name only two, might be part of the follow-up team.

COST ESTIMATE

Currently, the level III perinatal centers that the department funds receive $35,000-$65,000 each per year for the follow-up program. This gives a total annual budget of $390,000, including maternal and child health funds, which are now limited in their potential for growth.

To provide follow-up for all the children who are at risk, an annual increase of $510,000 is needed, for a total annual budget of $900,000 per year. This will require an appropriation of state funds.

Benefits Versus Costs

Can the benefits and costs of a program to follow up all infants who are at high risk of mental retardation and handicapping conditions be computed? The California Association for the Retarded puts the answer this way:

> The cost-effectiveness of *all* prevention as a *statewide program* can be verified. But cost-effectiveness arguments promoting one *type* of prevention program over another have little merit, especially to parents of a child who might be handicapped were it not for the administration of a specific "expensive" service. In fact, each successful effort that prevents a child from being handicapped is cost-effective for that child (1979).

Greenspan evaluated the cost-effectiveness of cases in the Clinical Infant Development Program (Prince Georges County, Maryland), in which the primary patient was the newborn infant who received preventive services for approximately three years, with services rendered to the parents and siblings, too. He hypothesized five different outcomes, from total dependence on government support to total self-support. Depending on the hypothesis, the results show a savings to society of $93,000-$145,000 in 1981 dollars (Greenspan 1983). The cost-benefit ratios for the five outcomes ranged 1:5- 1:7.

Again, the United States General Accounting Office reports that every dollar spent to screen newborns with a battery of tests to diagnose treatable conditions that cause mental retardation saves more than $20.00 for programs to serve the retarded (United States Department of Health, Education, and Welfare 1978).

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CAMP SUNDIAL
CHESTER, N.J.

CHAPTER 16

IMMUNIZE AGAINST INFECTIOUS DISEASES

RECOMMENDATION

We can now identify a number of pre-, peri-, and postnatal infections that contribute, in significant part, to central nervous system damage, including mental retardation. Vaccines have had great success in preventing the usual childhood diseases.

Many infectious diseases are known to cause mental retardation in a signficant portion of children who contract them. While not all diseases for which immunization is possible cause mental retardation, all put children, including children with mental retardation, at risk. Further, the delivery system

that is required for immunization should be fully utilized for prevention of all diseases for which a vaccine is available. We find that, in some cases, preventive measures are available but have not been implemented.

As our ability to control infectious diseases develops, we need more resources for immunization, education, diagnosis, and research. For these reasons, we recommend that:

1. Programs to extend immunization to all children should be improved, with special efforts to reach preschool children completely.
2. The system should be organized so as to prepare for possible use of new vaccines as they are developed. The Department of Health is in support of an on-going campaign to promote immunization for all vaccine-preventable diseases. What is more, the department also supports an expanded follow-up and tracking system to complete the immunization of school children (Goldstein 1985).
3. Additional educational programs should be developed. For example, new mothers in hospitals should be informed about early and complete immunization of their children. Among these, the New Jersey Hospital Association's national model program should have continued funding.
4. The capacity of diagnostic laboratories in New Jersey to use the most up-to-date, rapid diagnostic methodologies should be improved. Early detection warns of the potentials for an epidemic.
5. Research projects should be designed to study identification and control of infectious diseases.

Funding at the level of $456,000 per year would provide for the educational program of the New Jersey Hospital Association and for viral diagnostic laboratory capabilities. Data were not available to determine the exact costs of extending coverage of preschoolers, of educational programs, and of research projects, but, in the past, these have proven cost-effective in other states.

RATIONALE

Childhood Immunizations

8,000 CASES OF MENTAL RETARDATION PREVENTED BY IMMUNIZATIONS DURING A TEN-YEAR PERIOD

Some of the diseases that lead to mental retardation can be prevented by vaccination. *Encephalitis* (inflammation of the brain) is one condition that can result from measles or mumps. These diseases cause severe brain damage. If just one child in New Jersey suffers brain damage owing to childhood encephalitis and needs to be institutionalized for life, current projections are that the cost will be $1 million over that one lifetime. One physically disabled, deaf, or mildly brain-injured child per year is one too many when some diseases that lead to these complications can be prevented by vaccination.

A new vaccine is now available to prevent still another disease that causes mental retardation. *Meningitis* in the infant and young child has been clearly associated with neurologic sequelae in up to 50 percent of afflicted individuals (in some series). A realistic estimate of sequelae for children with *meningitis* treated in New Jersey is approximately 15 percent, with mental retardation resulting in approximately 5 percent.

The leading cause of bacterial meningitis is hemophilus influenzae type b. It causes approximately 12,000 cases of meningitis annually in the United States and most cases occur in children aged under 5 years. The mortality rate in this disease is 5 percent and neurologic sequelae are seen in up to 25-30 percent of survivors. Recently (April 1985), *hemophilus influenzae* type b polysaccharide vaccine was licensed and is presently recommended by the state Department of Health for all children at 2 years of age. The addition of this vaccine to our immunization program will offer significant protection against a major cause of bacterial meningitis in young children.

According to the recommendations of the American Academy of Pediatrics and of the Centers for Disease Control, the entire series of immunizations against diphtheria, tetanus, pertussis, polio, measles, mumps, and rubella should be completed by age 18 months. Completion of the series has a multiplier effect, because unimmunized children may spread disease to unimmunized adults, including pregnant women. The immunizations that the academy recommends are shown in the accompanying schedule.

RECOMMENDED SCHEDULE FOR ACTIVE IMMUNIZATION OF NORMAL INFANTS AND CHILDREN

RECOMMENDED AGE	VACCINE(S)	COMMENTS
Months		
2	DTP(a), OPV(b)	Can be initiated earlier in areas of high endemicity
4	DTP OPV	A 2-month interval is desired for OPV to avoid interference
6	DTP OPV	OPV is optional for areas where polio might be imported (e.g., some areas of the Southwest United States)
12	Tuberculin Test (c)	May be given simultaneously with MMR at 15 months
15	Measles, Mumps, Rubella (MMR)4	MMR preferred
18	DTP OPV	Consider as part of primary series — DTP essential
Years		
2-6	HIP (f)	18 months for children at high risk
4-6	DTP OPV	Up to seventh birthday
14-16	Td (e)	Repeat every 10 years for lifetime

SOURCE: New Jersey Hospital Association 1983

(a) DPT: Diptheria and tetanus toxoids with pertussis vaccine
(b) OPV: Oral, attenuated poliovirus vaccine contains polio-virus types 1,2, and 3
(c) Tuberculin Test: Mantoux (intradermal PPD) perferred
(d) MMR: Live measles, mumps, and rubella viruses in a combined vaccine
(e) Td: Adult tetanus toxoid (full dose) and diptheria toxiod (reduced dose) in combination
(f) HIP: Hemophilus influenzae B

COST-EFFECTIVENESS OF IMMUNIZATION PROGRAMS

The benefits of immunization are well illustrated by savings attributed to the licensing of the measles vaccine in 1963. Because of vaccination programs, during the years 1963-1972, almost 24 million cases of measles were prevented, 2,400 lives saved, and almost 8,000 cases of mental retardation were prevented resulting in a savings of $1.3 billion nation wide (Witte and Axnick 1975).

Immunization of children of all ages has begun to be effective in New Jersey, as suggested by the overall decreases in the number of cases of diseases for which immunization is available, reported in Table 16-1.

Table 16-1. — Numbers of reported cases of disease, by year, for New Jersey, 1978-1983

Number of cases	Year					
	1983	1982	1981	1980	1979	1978
Total	126	104	354	1,087	1,038	1,857
Rubella	7	16	89	95	384	1,596
Mumps	51	58	120	199	592	177
Measles	29	12	131	775	60	83
Pertussis	35	18	14	17	1	0
Tetanus	4	0	0	1	1	1
Diptheria	0	0	0	0	0	0
Polio	0	0	0	0	0	0

SOURCE: New Jersey Department of Health 1984

It is not possible to determine the degree to which the decrease in the number of cases reported in Table 16-1 is owing to *preschool* immunization and the degree to which the decrease is owing to *school-age* immunization programs. However, we were able to collect data on the extent of immunization in the two groups.

EXTENT OF THE IMMUNITY OF CHILDREN IN NEW JERSEY

School-Age Children Have Their Immunizations "Completed"

New Jersey has had a program to immunize school-age children since 1974 (Witte and Axnick 1975). The New Jersey Department of Health has been monitoring immunization of school-age pupils, grades K-12. Data reported by school nurses and administrators in the public and private schools and in preschool programs, such as Head Start, say that 97.3 percent of school enrollees "meet all requirements" (New Jersey Department of Health 1984).

Preschool Children Are Less Likely to Have Their Immunizations Completed

Immunization of preschoolers is in the domain of private physicians, child health conferences, and various preschool programs, such as Head Start.

When the New Jersey Department of Health surveyed two-year-olds in 1980, it found that 78 percent had completed the series of vaccinations (New Jersey Department of Health 1980). Even with a hospital-education program in place, some 20,000 two-year-olds were probably not protected against preventable diseases during the period covered by the survey.

For this survey, the department followed a survey design from the Centers for Disease Control. The Department of Health surveyed the parents of 600 two-year-olds in 1977 by mail, telephone, and field visits. Responses from 594 families show that large numbers of parents do not see that their infant's immunizations are brought up-to-date, as shown in Table 16-2.

Table 16-2. — Percentages of two-year-old children who were found to have zero doses administered, for a sample of New Jersey children, 1977

Disease	Percentages for survey year		
	1980	1979	1978
Mumps	18.7	25.8	45.1
Rubella	14.3	18.9	26.8
Measles	9.0	14.5	14.5
Polio	2.3	1.8	1.3
Diphtheria, Pertussis, Tetanus	2.1	1.4	0.4

SOURCE: New Jersey Department of Health 1980

Children who are at highest risk appear to be more likely not to be immunized, the survey showed. When the data were analyzed for socioeconomic characteristics, it turned out that less-educated mothers of three or more children were those who did not see to the completion of their children's immunization, in 71 to 89 percent of cases (New Jersey Department of Health 1980). It seems that these mothers tend to comply with the schedule for visits to a provider for examinations and vaccinations for about the first six months of the child's life, but thereafter do not return to a provider unless the child is ill (Mojica 1984).

Why do these mothers not see that their children are immunized? Are they merely negligent? Are they not aware of the necessity of immunization? Are they unable to get services? None of these questions has an answer, given the state of our knowledge. Knowing that less-educated mothers of larger families are more likely to neglect immunization *suggests* what the problems may be, but we cannot *know* what the problems are without further research.

We certainly do not assume that these mothers are all neglectful or uncaring, for the most part. The Illinois Department of Health concluded from a study of mothers of two-year-olds that:

> ...the problem does not appear to be a lack of information — parents who have received written information about immunization and [who] obtain health information from various sources are not more likely to immunize their children than [are] parents who do not. Rather, we suggest that the problem may be *due to a lack of concern about or confusion over the number of shots necessary for adequate immunization* (Illinois Bureau of the Budget 1979).

PARENT EDUCATION

This suggests a need to educate parents.

As Table 16-3 shows, more than 80 percent of children in New Jersey are born into families whose mothers have perhaps completed high school. Health education courses in schools should cover the need to immunize young children.

Table 16-3. — Numbers and percentage of children ever born to women aged 15-24 years, by years of school completed, for New Jersey, 1980

Years of school completed by mother	Children ever born	
	Number	Percentage
Total	**141,781**	**100.00**
Elementary school		
0-7 years	6,593	4.65
8 years	8,433	5.95
High school		
1-3 years	46,136	32.54
4 years	63,286	44.63
College and more	17,333	12.22

SOURCE: United States Department of Commerce 1983

This implies a need for health education in two ways: there are many mothers who are probably not well educated about health care, yet many of these mothers are educated enough that they can benefit from community education programs.

The Surgeon General, the Centers for Disease Control, and the American Hospital Association recommend three components for programs that address immunization (United States Department of Health and Human Services 1983).

1. Education of new mothers in hospitals about immunization
2. Identifying, tracing, and providing outreach and reminder services to parents of children who are determined to be at greatest risk of failing to complete the series
3. Effective provider-based reminder systems to recall children for booster immunizations

The New Jersey Hospital Association invented and has put into place the national model for hospital education. This program reaches 90,000-100,000 new mothers each year with education and follow-up programs.

First, the association's educational programs in 87 agencies (74 hospitals, 9 health centers, 1 midwife center, and 3 clinics) inform new parents about the necessity of early and complete immunization, about maintaining up-to-date records, and about local health services.

Second, the association's follow-up and tracking system has been developed and operates now in nine hospitals and in several clinics and health centers. Reminders about immunization are telephoned to parents, and appropriate referrals are made for mothers of children aged 3, 8, and 18 months. High-risk mothers are those who are aged under 19 years, who have less than 12 years of formal education, and who display other socioeconomic characteristics.

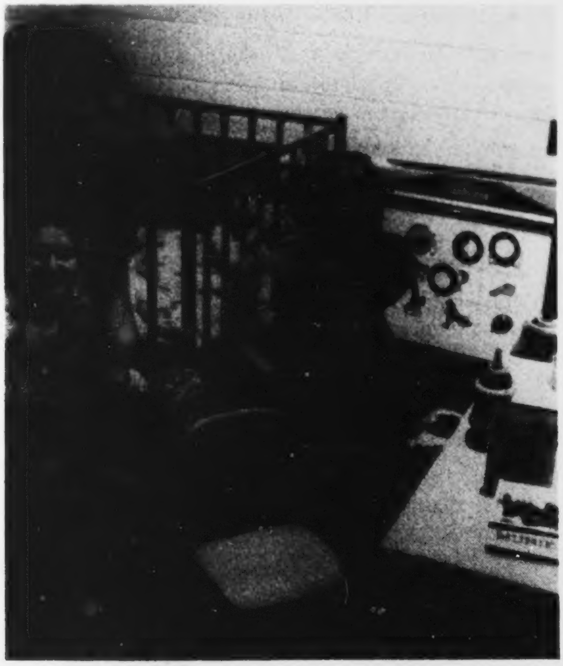
The Centers for Disease Control in Atlanta told the council that all programs in the nation are modeled after New Jersey's program for hospital education (Beimiller 1984).

We recommend state funding for the hospital association's educational program on immunization.

The hospital association's immunization education staff should coordinate its work with the Division of Epidemiology and Disease Control of the New Jersey Department of Health to design an immunization system for tracking so aggregate data can be collected on "compliance" over a three-year period. The association should provide a chairperson for a committee to plan, implement, and evaluate this research.

Since the New Jersey Hospital Association's program is designed with follow-up and tracking in place, its program seems ideally suited to following up and tracking the mothers and children who are at highest risk of not completing the series of vaccinations. In cooperation with the New Jersey Department of Health, a second systematic survey of "compliance" among mothers of preschoolers should be carried out. The survey design for 1977 should be revised and updated to permit follow-up of the population at high risk over a two-year period. Both the New Jersey Hospital Association and the Division of Epidemiology and Disease Control have indicated a willingness to cooperate in such a survey.

The data that would be collected, in an aggregate (non-invasive) form, could be used to determine how many preschool children actually are immunized, how effective hospital education programs for immunization are, and how programs can be improved.



CONTROL INFECTIOUS DISEASES IN MOTHERS

Maternal infections that affect the fetus have been more clearly identified in recent years. These include the group known by the acronym, "TORCHES":

- Toxoplasmosis
- Rubella
- Cytomegalovirus
- Herpes simlex
- Syphilis

Educational programs need to be developed to inform physicians and other health professionals about proper treatment of congenital neonatal, perinatal, and childhood infections. For instance, physicians should be advised that the main technique for the prevention of perinatal herpes varicella zoster is the use of zoster hyperimmune globulin in situations when the neonate is at risk. A vaccine is being developed for this disease but is not yet approved.

IMPROVE LABORATORY DIAGNOSTIC FACILITIES

The sooner diagnosis is made, the sooner treatment can begin, of course; and prevention programs in particular need advanced diagnostic laboratories. The council received two proposals for improving diagnostic laboratory facilities.

One proposal was that there be developed viral diagnostic laboratories at each of the three branches of the University of Medicine and Dentistry of New Jersey. This would effectively *regionalize* laboratory facilities and make for the use of the most up-to-date, rapid diagnostic methodologies available and for more timely diagnoses of infectious diseases. By locating the laboratories at the medical schools in Camden, New Brunswick, and Newark, all parts of the state would be covered.

A proposal received in response to this suggestion was that the New Jersey Department of Health make needed improvements further to *centralize* diagnostic facilities in Trenton. The improvements suggested include:

1. Reducing the time required to obtain results by incorporating direct testing by enzyme immunoassay and immune electron microscopy for antigen in clinical specimens as a screening procedure that, in a number of instances, would obviate the need for inoculation into host systems for isolation attempts (herpes simplex, cytomegalovirus, and chlamydia, for example).

2. Expanding the now limited use of immunoglobin-class-M-specific tests (indirect fluorescent antibody) to provide shorter turn-around time and single-serum diagnostic testing

3. Implementing the routine use of indirect fluorescent antibody assay for all Epstein-Barr virus requests, instead of the slower, nonspecific heterophile tests

4. Using and developing new DNA-probe techniques for rapid identification of viral isolates

5. Computerizing the receiving and reporting of data

6. Encouraging research into the use and development of hybridoma technology and methods of identification and quantification of class-specific immunoglobins that would permit the separation of maternal and fetal antibodies (Shahied 1985)

ENCOURAGE RESEARCH PROJECTS

Research projects should be designed to study the identification and treatment of infectious diseases. Specifically, there might be a study of the effective use of prepregnancy or early pregnancy screening for cytomegalovirus,

toxoplasmosis, and herpes simplex; and of third-trimester and postpartum techniques for identifying beta strep group B and gram negative infections.

An experimental vaccine is available for the prevention of cytomegalovirus, but it has not been extensively tested. A major research thrust could be the study of prepregnancy or early pregnancy serologic screening for cytomegalovirus. This would allow one to document early gestational primary infection.

Prepregnancy or early pregnancy serologic determinations for toxoplasmosis would allow for the documentation of acquisition of primary toxoplasmosis during the trimesters of pregnancy in which it is associated with significant rates of affliction.

Presently, there is no vaccine against herpes simplex virus infections. The effective use of appropriate genital cultures during pregnancy to document the presence of herpes simplex virus infections and allow for elective cesarian sections in positive women could be studied.

For perinatally acquired beta strep group B infections and gram negative infections, infants at risk can be documented by doing assays on maternal blood, looking for protective antibody levels. It is also possible to narrow down further the infants at risk, at least in the beta strep group B. Research into effective use of these techniques is needed.

Cost Estimate for Immunization Education

The council was not able to determine all the funds that would be required for immunization education programs.

The New Jersey Hospital Association reported that their program needs $56,000 to salary a director and staff assistant and provide clerical support, and that this program had lost the fiscal support of the New Jersey Department of Health, owing to budget cuts.

We were not able to discover what funds might be required by the New Jersey Department of Health for education programs, however. In a memorandum, the Commissioner of Health said:

> The Department of Health is very supportive of educational programs for expectant and new mothers which impart information regarding behavior patterns so as to prevent infectious diseases (such as toxoplasmosis) and which emphasize the benefits and importance of early and complete immunizations of their children. Such programs

and printed materials should be available in clinics, health centers, hospitals, and private offices (Goldstein 1985).

In another memorandum, however, the department pointed out that the educational programs and immunization programs have yet to be designed:

> We do endorse the concept of educational programs for new mothers...[and] for physicians. We are unable to properly support the monies proposed for this activity without the simultaneous submission of a budget for this activity which would permit a rational examination of these expenditures (Parkin 1985).

The point of this is that for educational programs to be begun on an effective scale, there has to be funding and a mechanism for coordination, such as is proposed in our chapter, "An Office for Prevention Programs."

Cost Estimate for Improving Diagnostic Facilities

While the council did not receive a detailed budget for viral diagnostic facilities suggested for three sites of the University of Medicine and Dentistry, the needs of diagnostic facilities at the state laboratory in Trenton were presented in detail and are summarized in the accompanying tabulation.

ITEM	DOLLARS
Total	**400,000**
Personnel	
Supervising, principal, and senior virologists; laboratory technician; clerk	172,000
Instrumentation and equipment	
Centrifuges, microscope, reader-printer; scanning densitometer, electrophoretic equipment, DOT blotter manifold	71,600
Computerization	
Mainframes and laboratory terminals	136,800
Reagents and specimens	19,600

Cost Estimate for Research

The council was not able to estimate the funding that would be effective for research projects, given the limited time of its work.

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CHAPTER 17

ESTABLISH A TASK FORCE ON EARLY PERIODIC SCREENING, DIAGNOSIS, AND TREATMENT IN SCHOOL SETTINGS

RECOMMENDATION

The Early Periodic Screening, Diagnosis, and Treatment (EPSDT) program reimburses preventive health care for medicaid-eligible children. The program covers the full range of childhood health problems and is intended to cover ongoing preventive health care for children and families who do not have a regular pediatrician, especially those who make inordinate use of emergency room facilities for lack of pediatric care in the community.

Few of the eligible children avail themselves of these services in New Jersey, however. Since schools are focal points of activity in the lives of families,

EPSDT services should be established as adjuncts to the settings of 10 high-risk school districts for children who are eligible for medicaid. This should include a strong preschool component.

In the school setting, EPSDT services can be organized to reach entire families to detect needs for genetic and teratologic counseling, treatment and prevention of substance abuse, immunization and nutrition, and risks for preterm births, adolescent and teenage pregnancy, birth defects, malnutrition, lead poisoning, and child abuse and neglect.

Pilot projects should include a pediatric consultant and a pediatric-nurse-practitioner and meet the "child health guidelines" set by the American Academy of Pediatrics.

The project should be designed to make maximum use of referrals to pediatricians in the community.

We recommend that the Department of Human Services fund the work of a committee to extend EPSDT programs to the 10 school districts in the state that have the highest percentages of pupils who are eligible for medicaid. This committee could bring together the local school boards; the local school districts; the advisory committee of the Division of Medical Assistance; local departments of health; concerned officials from the Departments of Health, Human Services, and Education; nurses; physicians; teachers; pediatricians; adolescent medicine physicians; and parents to develop a plan tailored to each school district. Evaluation of each program should be included as part of the plans.

To fund the committee for two years would require $252,000.

RATIONALE

Early Periodic, Screening, Diagnosis, and Treatment

The EPSDT program is a federally-sponsored medicaid program administered by each state, which reimburses for health care provided to medicaid-eligible children aged under 21 years.

The program is intended to provide comprehensive preventive care, as the acronym, EPSDT, implies:

Early: assessing a child's health as early as possible, so that diseases and abnormalities can be identified in preliminary stages when they are most effectively treated

Periodic: assessing a child's health regularly at the key stages in development when problems are likely to occur

Screening: using standard procedures that quickly and efficiently determine if a child may be subject to a previously undiagnosed or untreated condition

Diagnosis: following up on screening with diagnostic tests that synthesize the health history and physical examinations

Treatment: referring children for treatment to health-care providers and assuring that they get the treatment prescribed

Services include outreach, case management, transportation, dental, vision, scheduling assistance, laboratory tests, and immunizations (American Academy of Pediatrics 1984).

In New Jersey, EPSDT is administered by the Division of Medical Assistance in the Department of Human Services. The department defines the program within the controls exerted by state regulations and the limits of conditions in New Jersey.

As of January 1985, new EPSDT regulations issued by the United States Department of Health and Human Services strengthen the concept of "continuity of care" and EPSDT services that meet "responsible standards of medical and dental practice." This regulation — the result of two years of intensive efforts by the American Academy of Pediatrics, the American and National Dental Association, the Children's Defense Fund, and state medicaid directors — means that a poor child could have a "medical home": services from the same physician from birth to age 18 years. A new emphasis on performance, a periodicity schedule, and program accountability reports should result in more consistent and coordinated care for youngsters.

It is particularly important at a point when New Jersey may initiate a program for the "medically needy" that the duration, frequency, and scope of EPSDT be maintained. (See our recommendation, "Insure the Medically Needy.")

Many Eligible Children Do Not Receive EPSDT Services

In 1982 in New Jersey, 351,000 children were eligible for EPSDT, but only 45 percent received services. At least 120,000 children were under "equivalent care," according to the Division of Medical Assistance (Stekert 1984). Our information does not specify how this care is *equivalent* to the schedule of services provided under EPSDT.

Most of the $198 million that was spent for services in 1982 for people aged under 21 years went to hospitalization and visits to physicians, as shown in Table 17-1, and not to preventive services, such as EPSDT is equipped to provide.

Table 17-1. — Millions of dollars and percentages of medicaid expenditures, by services, for persons aged under 21 years, for New Jersey, fiscal year 1982 and 1984

Service*	Expenditure			
	1982		1984	
	Dollars (millions)	Percentage	Dollars (millions)	Percentage
Total	**198**	**100**	**222**	**100**
Hospitals	83	42	95	43
Physicians	23	12	23	10
Out-patient departments	26	13	32	14
Dentists	10	5	9	4
Clinics	2	1	3	1
EPSDT	1	0.5	1	0.5

Visits to Physicians, dentists, and out-patient departments account for most of the services in 1982, as shown in Table 17-2.

Table 17-2. — Units and percentages of medicaid services, for persons aged under 21 years, for New Jersey, fiscal years 1982 and 1984

Service*	Services			
	1982		1984	
	Units*	Percentages**	Units*	Percentages***
Hospitals	40,462	11	36,978	11
Physicians	284,768	76	266,879	78
Out-patient departments	157,880	42	154,629	45
Dentists	123,964	33	113,784	33
Clinics	25,882	7	29,109	8
EPSDT	38,930	10	37,632	11

SOURCE: New Jersey Department of Human Services 1985

* Not numbers of persons

** Based on 375,859 medicaid recipients aged under 21 years

*** Based on 343,853 medicaid recipients aged under 21 years

In this attempt to represent what services are provided, the units of service do not represent numbers of children nor do percentages "really" sum to 100 because of overlap: more than one service may be received by the same child. According to these data, it is hard to say what percentage of children actually receive services for which they are eligible. If only 45 percent of children who are eligible for EPSDT actually receive services, however, the program appears to need to recruit more effectively.

The Division of Medical Assistance (New Jersey Department of Human Services 1984) reports these efforts for recruitment: annual mass mailing of a brochure to all eligible families and individuals; face-to-face informing of newly eligible and recertified families; outreach to participants who come up on the computer for rescreening by the EPSDT unit, and to their siblings; and projects such as health fairs and clown shows.

It does not appear that these efforts are fully successful. The Association for Children of New Jersey surveyed 2,200 Head Start families in Newark. Of the 80 percent who responded to the survey, 50 percent of the medicaid-eligible families said that they had never heard of EPSDT (Association for Children of New Jersey 1984).

The 14-18-year-old group is particularly underserved, yet this age group is most at risk for unintended pregnancy, substance abuse, suicide, and motor vehicle accidents (Children's Defense Fund 1984).

New Jersey's children do not often have medical visits. The Health Care Financing Administration reported that New Jersey is at the bottom one-third in the periodicity of medical visits for children in the age group up to one year, and again for children aged 13-21 years. For both groups, the average is two visits a year. The American Academy of Pediatrics has recommended a different schedule of eight visits each year (United States Department of Health and Human Services 1984).

This report indicates that there were 334,743 eligible children in New Jersey in 1983, of whom 39,077 were screened and only 450 were enrolled in a continuing care program. The most prevalent problems discovered in the EPSDT program are dental and vision problems, and this indicates low use of continuing care and preventive screening. The report says that 322 pediatricians are involved in screening and examinations, while only 11 are involved in a continuing care program.

Finally, the very low reimbursement rate for physicians in New Jersey is a cause for concern. *New Jersey has the lowest reimbursement rate of all 50 states,* with an average reimbursement of $7-9 for an office visit (In comparison, for our region, New York reimburses at the rate of $14.50, Pennsylvania at $11 and Connecticut at $18.) For examinations, New Jersey reimburses at the rate of $18-23, New York reimburses at $26.20, Pennsylvania at $21, and Connecticut at $18. Low reimbursement rates discourage the participation of physicians in the program.

Other States Deliver EPSDT in the School Setting

The Division of Medical Assistance has the opinion that EPSDT does not recruit more successfully because clients have freedom of choice, are not educated about preventive health, are not interested in preventive health, and because services under EPSDT are available under the general medicaid program.

These are good reasons for providing EPSDT services in free-standing clinics in the school system, as several states have set out to do.

There are various ways that the school setting can provide this service to its children (United States Department of Health and Human Services 1980).

> *The school may do just the outreach:* refer children who need treatment to local hospitals that Medicaid directly reimburses. (In Philadelphia, where the health code requires physicals in some grades, this system is used.)
>
> *The schools may screen* under the supervision of a physician, while the department of education contracts directly with local school boards and bills Medicaid. (Louisiana and Minnesota have introduced programs of this type.)
>
> *The school may provide services:* nurse practitioners screen and treat and refer children for treatment, while the city, as the fiscal agent, bills Medicaid. (This system is in place in the Hartford, Connecticut public schools.)

Two Model Programs in New Jersey Schools

Asbury Park and New Brunswick have begun using the EPSDT system in their schools.

In Asbury Park, the Board of Education provides a computer-printed alphabetical listing of student enrollment to the county welfare agency. First, the EPSDT unit of the county welfare agency counts the number of medicaid-eligible children to determine the basis for state reimbursement of administrative costs and prepares an anonymous sampling of the records for accountability reports. Second, the unit identifies new eligibles and counsels the parent and school child. If the client refuses EPSDT services, the case is eliminated from follow-up. This sharing of records does not breach confidentiality in the school setting.

In New Brunswick, a grant from the Robert Woods Johnson Foundation has permitted a free-standing clinic to be set up in one of six elementary schools. With the services of a nurse coordinator, social workers, and physicians from Middlesex General Hospital, the schools identify children who are eligible, inform the parents of the program (and ensure follow-up on getting treatment for children who participate), screen children following the EPSDT protocol, and refer children who need treatment to physicians and hospitals in the community, and ensure that children get the treatment needed.

Benefits

A number of benefits would come from putting EPSDT programs in schools:

1. Recruiting of all eligible children: virtually all school-age children are enrolled or known to the schools

2. Increasing referrals to physicians, dentists, and hospitals in the community

3. Reducing gaps and duplications in services: where schools refer children to private providers, resources are used more evenly and no one service sector is overloaded (the emergency room of the local hospital, for instance)

4. Releasing limited school-health funds for other purposes. For instance, in 1982, Atlantic City spent $238,438 for health-service salaries and expenses for 7,251 students. But, since 50 percent of its students are medicaid-eligible, the city could recover up to $77,000 for services provided to these students, 50 percent of which is reimbursed by the federal government through EPSDT. (There were 15,008 children reported to be eligible for the program in 1981 in Atlantic City, but there were only 2,949 screenings.) (Tetelman 1983)

5. Implementing the newly-instituted federal waiver program in New Jersey, "Medicaid Personal Physician Plan," which ensures 24-hour, 7-day a week primary medical care (Stekert 1984)

6. Improving pupil discipline, attendance, and performance

7. Improving the health of students and reducing in the long-term costs of health care

School Nurses Report Needs for Health Care

The Governor's Committee on Children's Services Planning (1984) surveyed health services now offered in schools with a high number of medicaid-eligible pupils in 14 districts.

From a preliminary return from 10 districts, it was learned that schools have large numbers of medicaid-eligible students, as shown in Table 17-3.

Table 17-3. — Number of pupils and numbers and percentages of medicaid-eligible pupils, by district, for ten school districts, in New Jersey, 1983

District	Number of pupils	Lowest estimate of medicaid eligible	
		Number	Percent
Asbury Park	2,624	N.A.	39
Atlantic City	6,490	N.A.	[25-85]
Hackensack	4,114	N.A.	N.A.
New Brunswick	4,381	2,748	[35-100]
Newark	55,921	27,738	50
Passaic	6,369	4,435	70
Paterson	31,364	10,832	34
Union	6,271	245	4
Union City	7,582	2,177	29
Camden	18,839	N.A.	[34-99]

SOURCE: Governor's Committee on Children's Services Planning 1984

N.A. means not ascertained.

birthweight, infant mortality, inadequate prenatal care, and socioeconomic status poverty areas (New Jersey Department of Health 1984).

The school nurses report that every school district needs more funds for services. The annual costs to school districts for the services that they now provide range from $230,000 to over $1 million.

There is a wide range of variation in costs and services provided. School districts spend $36-$72 per pupil on school health services now. Costs for physician consultation range $21,000-$266,000.

School districts now provide a wide range of services, including child-study-team evaluations; dental services; optometrist services; hearing, vision, tuberculosis, blood pressure, and scoliosis screening; immunizations; physical examinations; health histories; and first aid. Many districts refer their pupils to health personnel and social-service agencies in their areas.

When asked to list the needs they feel for services, the nurses consider the most common health problems they see and report needs for health-care providers, medical facilities, community support, clearer regulations, technical training, and coordination of services.

A Committee to Encourage EPSDT Programs in the Schools

We recommend that the Department of Human Services fund the work of a committee to extend EPSDT programs to the 10 school districts in the state that have the highest percentages of pupils who are eligible for medicaid. This committee could bring together the local school boards; the local school districts; the advisory committee of the Division of Medical Assistance; local departments of health; concerned officials from the Departments of Health, Human Services, and Education; nurses; physicians; teachers; pediatricians; adolescent medicine physicians; and parents to develop a plan tailored to each school district. Each plan should include an evaluation component. To fund the committee for one year would require $126,000, which should cover the cost of technical and clerical staff, meetings, travel, and overhead.

COST ESTIMATE

ITEM	DOLLARS
To fund a committee	126,000
Personnel	
Director	35,000
Executive assistant	25,000
Word-processing assistant	18,000
Fringe benefits	18,000
Meetings	15,000
Overhead	15,000

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CHAPTER 18

ENCOURAGE BREAST-FEEDING, EXPAND THE "WIC" PROGRAM, AND PROVIDE FOR PUBLIC HEALTH NUTRITIONISTS

RECOMMENDATION

Noting that good nutrition is one of the most potent influences for a healthy life, public health experts have concluded that nutrition should be prominent in medicine and in public health.

Twenty years of study of the biochemical and immunological properties of human milk now show that breast-feeding has a special place in promoting the health of newborns.

1. **Minimum standards for hospitals as to infant formula should be reviewed and standards should be developed for hospitals to encourage and support breastfeeding.**

2. A campaign to promote breast-feeding should be undertaken, including clinical training of all health-care professionals and promotion of public policies that permit working mothers to extend the period of breastfeeding.

The "Special Supplemental Food Program for Women, Infants, and Children" (WIC) was created by Congress to help improve the nutrition of the high-risk, low-income population. While WIC services are offered in every county in New Jersey, funds are adequate to serve only 37 percent of the estimated 169,000 individuals in need.

1. The governor should select an appropriate commission to hold public hearings throughout the state on the utility and funding of the WIC program and to report to him on these hearings along with recommendations.

2. New Jersey should consider matching the contribution made by the federal government to the state's WIC.

Nutrition should be included among the list of core activities of local health departments.

RATIONALE

In the past two decades, the effects of malnutrition on physical and mental growth have been studied for fetuses and infants.

Retarded *fetal* growth, resulting in premature and low-birth-weight infants, may occur in pregnant women who are under- or malnourished (President's Committee on Mental Retardation, n.d.). Malnutrition both limits skeletal growth and harms the brain and nervous system. It is known that nutritional deprivation before birth, and in the first 18 months of life, can reduce the number of brain cells the infant will have (Winick and Rosso 1969). This can impair learning and intellectual capacities. Children who are growth-stunted have smaller head circumferences, a reflection of reduced brain growth. Some of these adverse effects may not be reversed with rehabilitation (Palmer 1978).

As for older children, Dean (1960), Barrera-Moncada (1963), and Ramos-Galvan (1960) show adverse effects of malnutrition on growth, and a positive correlation between height and intelligence. Malnutrition enhances the risk of infection and this aggravates poor health and affects growth adversely. Habicht *et al.* (1974) show that supplemental feeding during pregnancy benefits birth weight. Winick and Noble (1966) show that brain cell growth is lower in malnourished animals and humans.

The costs to society of inadequate nutrition appear in:

-increased medical costs associated with low birth weight babies

-increased general medical costs for high-risk infants and children through their growing years

-increased educational or institutional costs for the mentally retarded and for children with learning disabilities

-increased costs for government subsidy programs

Breast-Feeding

The growth of nutrition programs in general, and of the WIC program in particular, has been accompanied by a renewed interest in breast-feeding, which has actually been out of fashion in our society.

BREAST MILK IS BETTER

The recent controversy over the substitution of infant formula for breast milk has generated much of the evidence that breast milk is better (Blackwell and Salsbury 1981).

First, human milk has features that manufactured formulas cannot duplicate.

Human milk varies in consistently identifiable stages, as the infant develops (Lawrence 1980). The colostrum, which is present in the first week to ten days, contains high concentrations of protein, fat-soluble vitamins, minerals, and important antibodies that the newborn cannot produce for itself and that cannot be produced in formula (Jelliffe and Jelliffe 1978).

By the second week, fats increase. Later on, each mother transmits antibodies that her body has developed in response to infectious organisms. Formula manufacturers have not been able to reproduce this fine-tuning of nutritional components (Cunningham 1981).

Formula-fed infants may require more food to attain approximately the same end point as human-milk-fed infants and may not obtain the same level of metabolic efficiency (United States Department of Health and Human Services 1984; Garza 1984).

Second, infant formula requires quality control in its use that is too stringent for many people.

Inadequate infant formula has caused serious health problems: a vitamin B6 deficiency led to convulsions and seizures; marginal folic acid levels and absence of vitamin C led to anemia; improperly heated formula and/or lack of iodine caused incidents of goiter; and a vitamin K deficiency led to prolonged prothrombin time in infants.

Adequate preparation requires correct quality of water, sterilization, and refrigeration. Sanitized water; electricity and refrigeration; and the ability to read English and to follow directions for mixing, using, and storing formula may be a risk among low-income groups and among recent immigrants.

Third, studies show that breast-feeding is important for establishing emotional bonds and psychological and physiological gratification.

PRACTICES SHOULD ENCOURAGE BREAST-FEEDING

Even though breast-feeding is a "natural function," it has to be learned and it is a complex relationship among more than mother and child. A complex of social, psychological, and physiological events can interfere with breast-feeding. Repeatedly, it has been shown that information and support to expectant mothers, changes in hospital routines in the perinatal period, professional training, and postpartum work are needed even to make breast-feeding possible in our society.

Breast-feeding has been so long out of fashion in our society that a wide range of practices discourage it. Hospital practices often convey messages that bottle-feeding is preferable to breast-feeding. Some practices that have been reported include:

1. Sedation during labor and delivery that impairs lactation and the abilities of parent and child to breast-feed

2. Indiscriminate use of lactation suppressants that inhibit the production of breast milk

3. Separation of mother and infant at birth that delays sucking and slows down the production of prolactin

4. Rigid hospital feeding schedules set for the staff's convenience

5. Routines that infants be bottle-fed in the hospital nursery unless specifically ordered not to, interfering with the supply-and-demand-process necessary to successful breast-feeding

6. Distribution to patients on discharge of free samples of infant formula and literature published by the formula companies

Women who seek prenatal care and receive counseling on feeding their infant, may be driven to bottle-feed. Less educated women are especially strongly influenced by the treatment and advice the hospital personnel provide.

Customary medical training and practices may interfere with breast-feeding, too. For example, the medical community so accepts bottle-feeding that physicians may *assume* a woman will bottle-feed. Women often do not see a pediatrician until after the child's birth, but it is the pediatrician, not the obstetrician, who receives the sparse medical training offered about breast-feeding.

PROGRAMS CAN ENCOURAGE BREAST-FEEDING

Programs can raise the prevalence and duration of breast-feeding. Accurate information and informed choices permit women to follow through on their needs.

In New York, changes have been made in the health code to encourage breast-feeding. Hospitals are required to instruct and assist those patients who might choose to breast-feed; and the medical profession is urged to instruct patients that human breast milk is the preferred product for infant feeding.

New York requires of its hospitals that:

1. at least one person on staff be thoroughly trained in breast-feeding physiology and management to be responsible for ensuring the implementation of an effective breast-feeding program
2. policies and procedures be developed to assist the mother to breast-feed, that include
    - prohibiting standing orders for anti-lactation drugs
    - placing the infant for breast-feeding immediately following delivery unless contraindicated
    - restricting supplemental feedings
    - providing that the infant be fed on demand
    - restricting distribution of discharge packs of infant formula
3. an educational program be provided as soon after admission as possible, to cover the nutritional and physiological aspect of human milk, establishing lactation, dietary requirements, disease and medication, sanitary procedures, and information sources

RECOMMENDATIONS ON BREAST-FEEDING

1. The minimum standards for hospitals as to the preparation and monitoring of infant formula should be reviewed and a requirement should be added for the instruction and assistance of patients who choose to breast-feed their infants. An educational program in hospitals should address common problems associated with failure to establish an adequate milk supply.

2. A statewide breast-feeding promotion initiative should be undertaken to involve the education system and the media; clinical training of all health-care professionals; support services; and research on benefits, contraindications, and strategies. A national breast-feeding promotion effort is being directed to health providers, expectant mothers, and the rest of the public. The United States Departments of Agriculture and of Health and Human Services have joined forces with professional organizations and voluntary agencies to promote the practice of breast-feeding.

Special Supplemental Food Program for Women, Infants, and Children (WIC)

One nutrition program that should be improved in New Jersey is the Special Supplemental Food Program for Women, Infants, and Children (WIC). Data gathered from 10 years of WIC program services, show that the combination of food supplements, health care, and nutrition education that this program provides are effective for thousands.

The WIC program was created by Congress to help improve the nutrition of the high-risk, low-income population. Pregnant, postpartum, and breast-feeding women; infants; and children were targeted because they are most vulnerable to the effects of malnutrition. Health problems associated with malnutrition in these groups include premature deliveries, low birth weight in infants, infant mortality, mental retardation, learning disabilities, retarded growth in children, and greater susceptibility to disease.

The council found three problems:

1. The 1985 state budget reports $30.6 million in federal funds for WIC. Next year, it is probable the federal government will freeze funds. New Jersey has been given a guarantee in writing that funds will be available, but not the cash flow that would be expected if these funds are to be available. The federal appropriation is now for a ten-month fiscal-year period, not for the twelve months on which a program operates.

2. There are no state general funds for WIC nor are there additional funds available through the Maternal and Child Health Block Grant.

3. Individuals enrolled in New Jersey WIC number 60,000, and 108,000 remain eligible but unserved.

This problem of underenrollment is growing in numbers, since the number of eligible persons in New Jersey has grown by 17,540, an increase of 11.6 percent since 1983.

DATA SHOW THAT WIC REDUCES INFANT MORTALITY AND MORBIDITY

Adequate data exist to evaluate the WIC program. WIC and health care agencies routinely collect information on the effect of WIC on pregnancy outcomes, birth weights of infants born to WIC mothers, weight gain of WIC prenatals, the hematological status of the WIC population, the infant mortality rate of the WIC population, and growth and development of infants and children.

A 1981 study on WIC by the Massachusetts Department of Health, showed significant decrease in incidences of low-birth-weight in infants of WIC mothers (Kotelchuck 1981). A 1978-1979 Harvard study showed WIC participation by pregnant women positively and significantly associated with increased birth weight (Kennedy 1979). A 1979 study at the University of North Carolina showed an increase of mean birth weight in black and hispanic infants of WIC mothers (Edozien *et al.* 1979). A Connecticut study reported similar results (Wallach *et al.* 1981).

New Jersey data from 1983 showed a low-birth-weight rate of 6.4 percent among infants born to WIC mothers, compared to a rate of 6.8 percent among all New Jersey-born infants, a lower risk group. Low birth weight correlates to infant mortality, which has also been reduced with WIC participation.

The WIC program's reduction of infant low birth weight has resulted in significant medical savings. For every one dollar spent on the WIC program, three dollars are saved in averted medical costs associated just with strengthening low-birth-weight infants enough to leave the hospital.

New Jersey data in 1983 showed other positive effects of the program, such as a reduction in anemia in young children from 5.2 percent at initial visits to WIC to 3.8 percent at follow-up visits (New Jersey Department of Health

1984). Anemia is associated with poor growth, short attention span, and impaired learning in young children.

Further, New Jersey data show improvement in the incidence of low height for age (15.5 percent initial versus 10.1 percent follow-up) and low weight for height (5.0 percent initial versus 3.6 percent follow-up) — signs of poor growth and contributors to health problems in young children. The WIC program has been associated with improved school performance and increased work productivity among its participants.

MANY AGENCIES NETWORK TO INCREASE OUTREACH EFFORTS

To maximize its impact on the health of participants, the WIC program works closely with other health care and social services agencies. A referral network among WIC and these agencies and programs assures that people potentially eligible for WIC are brought in to be screened and that WIC participants and applicants are channeled into other necessary services.

Services include routine preventive health care, comprehensive health services, immunizations, lead poisoning screening, dental care, Food Stamp Program, Aid to Families with Dependent Children (AFDC), child day care and Head Start, and counseling and other social services. The WIC program is targeted to the most high-risk groups through extensive outreach on the state and local levels. Information is disseminated in four languages (English, Spanish, French, and Vietnamese) to reach the most affected ethnic groups in our state.

The American Public Health Association, the American Dietetic Association, the March of Dimes, and the American Medical Association are among the agencies supportive of the WIC program.

CONTINUATION OF STATE WIC PROGRAMS DEPENDS ON STATE SUBSIDIES IN FUNDING

WIC is funded by Congress and administered by the United States Department of Agriculture. State governments receive federal WIC grants, which are then distributed to local WIC agencies. In New Jersey, the health department administers the program, determining policy and providing technical assistance. Local agencies hire qualified personnel (coordinators, nutritionists, and other health professionals, and clerical staff) to provide services directly to participants.

The New Jersey WIC program began in 1974 and has grown to an enrollment of 74,000 eligible people in fiscal year 1985. While WIC services are now offered by 24 local WIC agencies that operate 311 health care sites and cover every county in New Jersey, funds are adequate to serve only 37 percent of the estimated 169,000 individuals at risk. There is now a list of 2,500 who are eligible for services and waiting for them.

A program, designed to prevent health problems by improving the nutritional status of its target population, should not be frozen or cut in any year. With a 4 percent inflation rate, a freeze in 1986, for example, would require terminating the program benefits of over 2,500 women, infants, and children.

If the WIC program is to continue to produce such positive results, the legislature must be informed about cuts, and asked to contribute to the services from state funds, not just to keep program enrollment stable, but to permit a steady growth of services

RECOMMENDATIONS ON WIC

1. The governor and the legislature should designate a commission to review the question of WIC and other nutrition programs, hold public hearings, publish a summary of the hearings, and make recommendations.

2. New Jersey should consider matching the federal contribution for WIC each year. To reach at least the women eligible for the program in our state, if not their infants and children, would require $38,888,000.

Nutrition Programs Have Proved to be Effective

The incidence of mental retardation has been noted to be 13 times greater for children of low-income families than for those born to families of middle and high incomes. Some of this must be owing to malnutrition, and poor and less-educated persons are more likely to suffer malnutrition.

The consequences of poor nutrition are evident from the fact that 6 of the 10 leading causes of death in the United States have been linked to diet. The nutrition problems of the American public are reflected in:

1. The large number of women who have poor outcomes of pregnancy
2. Excessive infant mortality and impaired growth and development associated with low birth weight
3. High incidence of obesity with accompanying risks for hypertension and diabetes
4. Extensive dental disease in the population
5. Increased frailty and premature institutionalization among older adults
6. Premature death and disability owing to cancer and heart disease
7. Technology and environmental contaminants that raise public concern about the safety of the food supply
8. The shift of supervision of child health and nutrition to persons outside the family owing to the increase in the number of mothers who work

GROWTH OF NUTRITION SERVICES

One response has been the growth of the nutrition component of public health services. Nutrition services began in public health programs in the 1920s with passage of the Maternity and Infancy Act. The Social Security Act in 1935 expanded nutrition services in state health agencies. In the 1950s, federal funding for specialized programs for chronic disease, maternal and infant care, child health, and mental retardation led to a significant increase in the direct provision of nutrition services by trained nutritionists. During the 1970s, federal initiatives in comprehensive health planning and primary health care increased the scope and coverage of nutrition services.

Nutrition service programs have emphasized improving the nutrition of pregnant women, infants, children, and adults through screening and assessment, dietary counseling and treatment, nutrition education, follow-up; referral, and, in some cases, the direct provision of food.

Today, research shows that when nutrition services are integrated into health care, needed changes in diet and nutrition occur. As reported by the ASTHO Foundation (1983), for the Bureau of Health Care Delivery and Assistance of the United States Department of Health and Human Services:

1. The distribution of birthweight of infants born to high-risk mothers improves.
2. The incidence of iron deficiency anemia lowers.
3. Long-term and maintained reductions in weight are achieved.
4. The incidence of dental cavities is reduced.
5. Serum cholesterol and the incidence of heart attacks are reduced.
6. Glucose tolerance in persons with diabetes improves.
7. The blood pressure of hypertensive patients is reduced.

WHAT A NUTRITION PROGRAM DOES

The functions of a nutrition program vary according to the size, nature, and organization of state and local public health agencies. However, there is a core of basic functions that every nutrition program should perform. These are leadership for community planning and evaluation, administration and management, coordination, consultation, quality assurance, education, direct nutrition care, and applied research.

Direct nutrition care consists of screening to identify high-risk persons; assessments of nutritional status; nutrition care planning; and counseling, treatment, follow-up, and referral to agencies (Crump 1984).

WHAT A PUBLIC HEALTH NUTRITIONIST DOES

A public health nutritionist provides planning, coordination, and technical assistance to develop resources already in the community and to develop new resources.

1. Leads in assessing needs for nutrition services
2. Works with health officials to develop nutrition policy and program requirements
3. Determines the adequacy of nutrition services in relation to the goals and objectives of an agency
4. Directs planning, management, and evaluation of the nutrition program
5. Coordinates nutrition activities in programs that cut across administrative units
6. Gives technical assistance to, consults with, and trains the staff of an agency

7. Provides or arranges direct services to clients
8. Works with other state and local agencies to develop interagency relationships and conduct joint educational, service, or research programs

RECOMMENDATION TO PROMOTE NUTRITION SERVICES

The New Jersey Department of Health should include nutrition in its list of core activities, so that the services of a registered nutritionist would be available to all the populations in the jurisdiction of each local health department.

Cost Estimate

New Jersey should consider matching the federal contribution for WIC each year. To reach at least the women eligible for the program in our state, if not their infants and children, would require $38,888,000.

Two years would be required to organize and hold adequate public hearings, publish the results, and develop recommendations for the governor. This would necessitate either a legislative or executive commission, in but not of any department, composed of three staff and clerical support. This would cost $200,000 per year for two years.

Our recommendation to add nutrition to the list of requirements that the state health department makes for the local health departments would cost $50,000 for each local health agency. This would require the services of a public health nutritionist, a part- time secretary, office space, and support services. Changes in public health funding would be required to support this activity in local health departments statewide.

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CHAPTER 19

TEST EVERY CHILD IN HIGH-RISK AREAS FOR LEAD POISONING AND ABATE THE HAZARDS OF LEAD

RECOMMENDATION

Lead poisoning is a preventable cause of mental retardation in children. Today, at least 220,000 preschool children in New Jersey are living in conditions known to be characterized by high exposure to lead. In 1984, 70,242 of our children were screened, and *1,317 were found to be lead burdened.*

New Jersey's children must be protected from this toxin. Therefore, it is in the best interest of the people of New Jersey to mount an aggressive campaign for the elimination of lead poisoning. Since lead poisoning is a societal problem, we recommend that the problem be approached on two fronts.

1. **Primary prevention programs:**

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A. Parents should be instructed in ways to protect their children from lead poisoning. An educational program to inform the public of the seriousness of the lead poisoning problem should be undertaken. Important components of this program should be the teaching of parenting skills and good nutrition, with emphasis on breast-feeding.

B. A concerted effort needs to be mounted to rehabilitate the housing stock, since much of the severe lead poisoning in children occurs today because of ingestion of lead paint and plaster from dilapidated housing.

By rehabilitation we mean instituting preoccupancy inspection of residences, requiring that dwellings be abated of sources of lead upon transfer, and establishing a housing-risk registry.

C. The state should develop legislation, regulations, and disincentives that should include (1) phasing out the sale of leaded gasoline; and (2) banning the sale and use of lead solder in plumbing for drinking-water systems, if federal regulations that are now under discussion are not implemented immediately.

D. The state should ensure that all publicly sponsored (state, county, and municipal) facilities maintain a safe living environment, free of exposure to lead or other harmful substances where there is risk of lead poisoning. Funding should be made available to provide for abatement or removal of such substances when they are identified.

2. Secondary treatment programs for lead poisoning.

A. Increased effort must be made to identify children with elevated lead levels at early stages (that is, prior to the onset of clinical symptoms) so that medical intervention can prevent the long-term consequences.

New Jersey should allocate $5.5 million to the Department of Health to test every child in high-risk areas of the state and to pinpoint sources of lead poisoning.

B. Temporary, alternative, safe housing must be developed to provide temporary respite to victims of lead poisoning while sources of lead are being abated in their dwellings.

C. Financial-aid programs should be available, on a graduated-fee scale, for families with a lead-poisoned child to assure follow-up, diagnosis and therapy, and abatement of hazards of lead in the home.

3. Research should be supported further to document the effects of slightly elevated blood lead levels on neurodevelopment and to trace the sources of lead contamination.

RATIONALE

Lead, a useful but potentially toxic metal, has been used in our world at least since prehistoric times. Lead is introduced into the environment by both natural and human activities. Over the last several hundred years, the major source of ecologically active lead has changed, however, from nature (principally volcanic ash and sea spray) to culture (principally pigment and petroleum products) (Settle and Patterson 1980).

Lead Has a Greater Effect on Children

Lead appears to have a greater effect on the developing organism than on the fully mature individual (United States Department of Health and Human Services 1985). Lead is a protean poison; that is, it affects enzymes that catalyze a wide range of essential body functions. Recently, reports have appeared that relate prenatal exposure to lead to fetal wastage and congenital anomalies (Needleman *et al.* 1984; Angell and Levery 1982). Evidence is accumulating that lead, even in subclinical levels, causes defects in central nervous system development (Needleman *et al.* 1979).

The developing child nearly always goes through a phase in which he learns about his world through his sense of touch and taste. Normal hand-to-mouth activity brings much material to the mouth of a toddler. This activity produces an incidence of accidental ingestion of intoxicants among toddlers several times greater than among the rest of the population. The activity usually disappears completely by age five years and is usually not a significant problem by age three years. Various factors appear to influence the disappearance of this habit. Such things as poor nutrition, poor parental supervision, and delayed weaning appear to prolong hand-to-mouth activity (Marcus, Damaso-Diaz, and Ziering 1978; Hunt, Hepner, and Seaton 1982; Singhi, Singhi, and Adwani 1981).

Clinical Lead Poisoning

It is clear that extreme elevations in total body accumulation of lead that result in elevated blood lead levels cause a syndrome that affects all body systems. The central nervous system is particularly sensitive to lead since it is undergoing a major development at the time when the infant is most likely to be exposed to elevated levels of lead.

MENTAL RETARDATION

The incidence of mental retardation among lead-poisoned children is significantly greater than among the general population. In cases in which lead poisoning manifests as coma or seizures, the incidence of mental retardation exceeds 66 percent (Albert *et al.* 1974).

CONVULSIONS

Convulsions are a common presentation of increased pressure on the brain. Lead poisoning is known to produce such increased pressure; thus, seizures frequently occur as a consequence of lead poisoning. These seizures place the victim at a serious risk of developing brain damage as a result of anoxia, or lack of oxygen to the brain. Further, lead poisoning more than doubles a person's risk of developing a chronic seizure disorder *(Ibid.)*.

ACUTE PROBLEMS

Untreated, serious elevations in blood-lead levels may produce convulsions, coma, and death. Although rare today, these effects are still a clear memory to all who treat lead-poisoned children. It is unclear what the incidence of lead poisoning in sudden and unexpected deaths in children really is. A recent review of "fixed" postmortem tissues from such deaths that occurred in the 1960s and 1970s in Michigan suggests a much greater incidence than was expected (Meester and Eisengo 1984).

Subclinical Effects

Increasing interest is being paid to those children who develop elevations in their blood lead levels below those thought to require medical intervention but above those of the general population (United States Department of Health and Human Services 1985).

LEARNING DISORDERS

Several reports have appeared in the literature that describe the effect of low-level lead poisoning on learning and cognitive ability. Needleman (1979) presents convincing evidence that lead poisoning, even in subclinical cases, produces a syndrome of cognitive and learning disorders. An attempt was made to correct the deficiencies of the original work. A later study that sought to control for faults in the original work reports a similar, although not statistically significant, trend toward lower cognitive development and learning disorders (Smith *et al.* 1983).

BEHAVIOR

Needleman's study suggested a relationship of nonadaptive school behavior to elevations in lead levels. This finding substantiates previous evidence that lead may be partially responsible for disruptive juvenile behavior and hyperactivity (David, Clark, and Voeller 1972). Evidence is mounting which suggests that adolescents who commit crimes have higher blood-lead levels than the general population.

HYPERTENSION

At least two reports have appeared that appear to link lead poisoning to hypertension in both children and adults (Jhaveri *et al.* 1979; Batuman 1983). Further, patients with end-stage renal disease for which no etiology can be found tend to have greater body burdens of lead than the general population (Wedeen 1982). This suggests the possibility that lead somehow interferes with normal renal function to produce hypertension and, eventually, renal damage. It is unclear whether lead plays any role in essential hypertension in adults, the major cause of morbidity and mortality in adult Americans.

Sources of Exposure

One major source of lead that causes significant lead poisoning is paint that contains lead pigments. Further, lead is found in the air in varying concentrations, and as a contaminant of a wide variety of foods and drinks.

LEAD-BASED PAINT

Paint that contains lead is still the most important source of lead exposure (United States Department of Health and Human Services 1985). One square centimeter of paint, a piece about the size of the fingernail on an adult pinky-finger, with only one layer of lead pigment that contains 10 percent lead by dry weight contains *more lead than the maximum* that a toddler may be permitted to take in daily. Houses that are old and that have been painted several times contain wood surfaces with considerably greater contents of surface lead.

AUTOMOBILES AND INDUSTRIAL SMOKESTACKS EMIT AIRBORNE LEAD

Lead is released into the air by both fixed energy users (for example chimneys and smokestacks of industry and power companies) and by mobile energy users (principally the automobile). In the case of the automobile, the lead is in the form of products of combustion of tetraethyl lead. This lead is both in an organic vapor form and in a particulate inorganic form (Yu, Vislay, and Edwards 1977; Salvage 1982).

Lead levels in people who live near major highways may be significantly higher than in those who live away from heavy automobile traffic (Caprio, Margolis, and Joselow 1974). However, the second National Health and Nutrition Examination Survey report suggests that there has been a gradual decrease in the blood-lead levels of Americans over the four-year period 1976-1980. This decrease appears correlated significantly with the decrease in the use of leaded gasoline.

It is interesting to note that the requirement to use lead-free gasoline was developed to protect the automobile's catalytic convertor, which originally was aimed at decreasing hydrocarbon emissions, not at lowering levels of lead in human blood. It is now possible to produce an automobile engine that meets the hydrocarbon requirement without the use of a catalytic convertor; thus the need for lead-free gasoline has disappeared.

CANNED FOODS ARE A SOURCE OF LEAD

A United States Food and Drug Administration (FDA) report in 1975 dealt with the lead content of commercially available foods (Jelinek 1982). The FDA indicated that it was unlikely that lead contamination in food could lead to significant lead poisoning. The survey indicated, however, that infants of two months to two years of age have estimated daily intakes of lead from food that range from 63-115 micrograms. This is below the suggested maximum allowable daily dose of 150-200 micrograms.

It must be understood, however, that this estimated daily intake is from food alone. Lead taken into a child by routes other than the gastrointestinal or from other sources represents an additional burden. The United States Food and Drug Administration (FDA) data suggest that the major source of food-borne lead is canned foods. This is particularly distressing if an infant is fed evaporated milk, which may still be found packaged in lead-soldered cans and which may be used by low-income parents. The FDA also reported on the low but real levels of lead found in raw fruits and vegetables, contaminated by the use of pesticides.

WATER PIPES SOMETIMES ARE A SOURCE OF LEAD

Lead may leach into the water that we use by way of plumbing, especially after water sits in pipes for several hours. Most plumbing in use today is copper, and most is connected with copper joints that are made by soldering together two pieces of copper tubing with lead-tin solder. Less commonly, certain older buildings have functioning lead pipes — a smaller, but potentially significant, source of lead. It does not appear that plastic plumbing materials, from which organic materials may be leached by water, can be assumed to be a safe substitute without considerable additional study and research. Since effective substitutes for lead-soldered plumbing are available, New Jersey should regulate the use of the soldering materials, if regulations that are now under discussion at the federal level are not implemented immediately.

Children at Risk

The National Health and Nutrition Examination Survey suggests that all children are at risk for lead poisoning but certain populations carry a somewhat increased risk. The young, black, inner-city child appears to be at increased risk, even when we take account of confounding factors.

Lead Poisoning Has Reached Endemic Proportions in New Jersey

The report of New Jersey programs to the Centers for Disease Control in 1982 documented incidence of new cases of lead poisoning in project cities at a rate at least twice that of the rest of the United States (United States Department of Health and Human Services 1982). Rates of over 10 percent were found in Newark and Jersey City, while an incidence of over 5 percent was generally found, with the highest rates in Essex, Hudson, Passaic, and Union counties. Thus, it can be said that lead poisoning reaches endemic proportions in New Jersey.

Recent data on lead poisoning among New Jersey children are shown in our chapter "Causes of Mental Retardation."

PRIMARY PREVENTION PROGRAMS

We recommend several programs as primary prevention tools for the elimination of lead poisoning. First is an educational program, second is a housing rehabilitation program, and third is the control of mobile and stationary sources of atmospheric lead pollution.

Education of Parents and of Parents-To-Be

Parents must be instructed in how to avoid lead poisoning in their children.

A public education program on the pervasiveness and seriousness of the problem must be undertaken. The continued existence of lead poisoning as a problem of children and the impact of lead poisoning on the child are not appreciated by the public. State and local agencies have designed and disseminated various education materials, filmstrips, and tapes, and they take advantage of media coverage whenever possible. But, owing to their limited funding, media campaigns cannot take top priority. Inspite of these efforts at public education, lead poisoning is still popularly considered either extinct or confined to the inner-city, where it is considered a rare disease at that. Because protection against lead poisoning depends so much on parenting skills and nutrition, education for these must be developed.

PARENTING SKILLS

Programs on parenting skills must be developed and incorporated into school curricula. Lead poisoning prevention should be a routine part of school curricula that goes beyond professional training programs for social-service professionals. Being a parent is not an easy task. Children no longer grow up surrounded by siblings and extended families. Many children do not experience first hand the development of a younger sibling and thus they enter the childbearing ages and adulthood with little information on normal child development and behavior. Lead poisoning and the means to avoid it must be a subject to be discussed.

NUTRITION

Educational programs with specific information about the prevention of nutritional deficiencies related to medical illness or to deficiencies that may predispose one to medical illnesses must be developed. The interplay of the environment and nutrition must be discussed.

Evidence appears strong that there is a relationship between mouthing activities related to eating and lead poisoning. A program to encourage breast-feeding needs to be promulgated. (See our recommendation, "Encourage Breast-Feeding, Expand the WIC Program....")Breast-feeding as the preferred way to feed infants must become a part of in-school health and child-development education. Education on weaning of children from either breast or bottle at 12-15 months must be considered, too.

The Department of Health should develop regional programs to encourage breast-feeding. These programs must address the education of the population as well as of pregnant women. Programs cannot wait until after a baby is born to try to educate mothers about breast-feeding. These programs can be expanded to provide education about normal child development and proper parenting techniques, preferably at a time more conducive to learning; that is, prior to a child's birth.

Programs to aid in providing proper nutrition to pregnant women and their children need to be strengthened. Pediatric involvement must be increased. Health care aides need to be trained in normal nutrition and how to provide it at the lowest possible costs. These health aides should be available as consultants to local keep-well stations and regional nutrition programs. They could go beyond the clinics and take mothers to the marketplace and show them how to use their limited money most effectively.

Housing Rehabilitation

The majority of severe lead poisoning in children occurs today because of the ingestion of paint and plaster from dilapidated housing. A concerted effort needs to be mounted to rehabilitate the housing stock.

PRE-OCCUPANCY INSPECTION

All residences must be inspected for integrity of construction and absence of health hazard before they are sold or rented to families in the childbearing years or who have children. Unsafe living quarters must be brought into compliance with health and safety standards or not sold or leased.

CODE ENFORCEMENT

Increased emphasis must be placed on the enforcement of current housing codes. Lead plumbing must be replaced with less toxic materials.

HOUSING-RISK REGISTRY

Every house or apartment found to have a potential health hazard should be listed in a registry kept by each local health department. This will allow a potential renter or purchaser to check on the health history of the living quarters prior to moving in. The registry would be updated regularly and would provide an important source of information to families who are looking for lead-free housing.

Control of Mobile and Stationary Sources of Atmospheric Lead Pollution

Lead is released into the atmosphere by both mobile and stationary emitters. A comprehensive program of legislation, regulations, and disincentives must be developed to control these sources of toxins.

MOBILE SOURCES

New Jersey should move swiftly to establish regulations that prohibit the sale of leaded gasoline in the state, if effective federal regulations that are now under discussion are not implemented immediately. The automobile that burns leaded gasoline is responsible for the majority of lead added to our atmosphere from mobile sources. Attempts are being made to regulate lead out of gasoline by the federal government. Certain municipalities, for example Chicago, have already moved to prohibit the sale of leaded gasoline within their jurisdiction.

A statewide regulation would affect all gasoline-powered tools as well as cars, since no leaded gasoline could be sold. Blends of gasoline can be used in engines built for leaded gasoline without harm to the engine. In this way, even large-scale users of leaded gasoline, such as businesses that have large fleets made up of older vehicles, can adjust to the change without loss. Further, the major oil producers are already geared up to produce unleaded gasoline in the amounts needed by vehicles in the United States.

STATIONARY SOURCES

All industries that use lead must be monitored closely as to their lead emissions. Heavy fines should be imposed for failing to comply with clean air standards.

Rehabilitation of Public Facilities

Elevated lead blood is found at a higher percentage among those tested *who are in the state's own institutions* than among persons tested in the general population.

State, county, and local governments operate or provide funding for community and institutional programs for thousands of children, the mentally ill, the mentally retarded, victims of domestic violence, and others in need of short- or long-term care. There are standards to govern life safety and other aspects of these facilities. In many instances, however, these programs are housed in older buildings that may contain lead paint or other potentially harmful substances.

As discussed elsewhere in this recommendation, there is evidence that lead in the blood can affect mental functioning and cause serious health problems at any age. An effort should be mounted to ensure that these vulnerable populations are not exposed to lead or other potentially harmful substances in any community or institutional setting.

SECONDARY TREATMENT PROGRAMS FOR PREVENTION OF LEAD POISONING

Until the goal of the elimination of lead poisoning is reached, we must have programs which aim to treat the problem. To this end, we recommend a screening program for the identification of lead-poisoned children, the development of regional facilities to house victims of lead poisoning until their homes are abated, and a financial program for families with a lead-poisoned child to ensure that proper measures are taken for the lead-poisoned child and for his or her living environment.

An Intensive Screening Program for Lead Poisoning

Increased effort must be made to identify children with elevated lead levels at early stages, that is before the onset of clinical symptoms, so that medical intervention can prevent the long-term consequences.

UNIVERSAL SCREENING OF CHILDREN AGED SIX MONTHS TO FIVE YEARS

Screening for lead poisoning, utilizing the cost-effective technique of erythrocyte protoporphyrin, should be done at least yearly on every child aged six months to five years. Although it is possible to delineate a population at greatest risk for developing lead poisoning, it is impossible to assure that all cases will be identified. The entire child population must be considered, in its entirety, as at risk.

Funding should be made available so that this can be done at the expense of society since the cost savings are to the society. Funding should come from public health sources and be in the form of free blood tests.

BUILT-IN FOLLOW-UP

A program for guaranteed follow-up of all positive screening tests must be developed. It is important to realize that if hundreds of thousands of children are tested, a substantial number will be found who need medical follow-up and evaluation. This can take the form of regional centers for referrals and of reimbursement of physicians for diagnostic evaluations. Our greatest fear is that the working poor would have the benefit of screening but be unable to afford the follow-up care.

Temporary Safe Housing

Respite care must be available for children and families whose dwellings are being abated of sources of lead, so as to minimize the risk of encephalopathy that is highest during the process of abatement.

A program of temporary, alternative, safe housing must be established to relocate families while their homes are decontaminated or until they can find appropriate housing elsewhere. All too often, children found to have lead poisoning, are admitted to hospitals for treatment, yet must be returned to the same lead-contaminated environment from which they came. Their living quarters cannot be decontaminated quickly enough. Many times, this results in the children's being exposed again to toxic quantities of lead and in the need for further hospitalizations and treatment.

Medication is available that can be administered orally to lead-poisoned children, after they have finished a course of treatment in the hospital, that will result in a cure of their poisoning. This medication must be carefully monitored and no further lead exposure can be tolerated during therapy.

Financial-Aid Program to Assure Medical Care and Home Abatement

A program of financial aid on a graduated-fee scale developed to assure follow-up, diagnostic and therapeutic care, and home abatement to low-income families. It is imperative that adequate funds be made available to guarantee that complete follow-up evaluations and therapy can be provided for all cases of lead poisoning found at the time of screening.

RESEARCH GOALS

Neurodevelopmental Research

The state must support a prospective, controlled study of lead and neurodevelopment. All current studies on the effects of lead on neurodevelopment are flawed by a host of problems with how the research was designed. New research should include work on the subjects of host response, why a person or a group of people appear to be at greater risk than others of developing lead poisoning, whether treatment alters the adverse neurodevelopmental effects, and whether there is a dose-related effect.

Sources of Lead

The state should develop a research model to determine if the stable-isotope technique can be used clinically to identify the specific sources of lead exposure of the citizen population of the state. A great debate is now flaring about the major source of lead contamination in the atmosphere and what constitutes the greatest threat to human life.

Technology exists to trace the source of lead found in nature and to trace the source of lead in individual organisms. The technique of stable-isotope determination may shed light on the role that lead contamination of food or air has, as opposed to the effect of lead-based paint on the development of clinical lead poisoning in children. Further, such a technique may be employed to trace the source of lead in individuals to its point source and, hence, aid in the enforcement of health codes related to lead contamination. New Jersey needs to develop an office or a program to support research of this kind.

COST ESTIMATE

In order to fund the programs we have recommended, New Jersey should appropriate $7,000,000.

ITEM	DOLLARS
Total	**$7,000,000**
Primary Prevention:	1,500,000
PLAN PROGRAMS TO ABATE HAZARDS OF LEAD;	
Provide alternative housing, financial aid, and support research	1,400,000
Rehabilitate housing stock: Inspect residences, enforce codes, and establish a housing-risk registry	50,000
Ensure safety in publically-sponsored facilities: remove sources of lead and abate lead-based paint	50,000
Secondary Prevention	5,500,000
TEST EVERY CHILD IN HIGH-RISK AREAS OF THE STATE	5,500,000

Primary Prevention: $1,500,000 to Begin Abating the Hazards of Lead

The New Jersey Department of Health estimated that *$2.9 billion* would be required to remove lead paint from the housing stock. Approximately 65 percent of the state's housing was built prior to 1960 and therefore, may contain lead paint. The cost estimate for removal of lead paint is $1,657 per unit.

But effective action can be taken at the local level. The city of Paterson, for example, has instituted an ordinance that requires housing to be freed of lead-based paint at transfer and when lead-based paint is detected by a health or housing inspector. In the first four months of this program, lead based paint was removed from 300 houses, and the program has not proved to be expensive to sellers, a burden to landlords, or expensive for the city to administer.

Given the high-cost estimated for a centralized program to remove lead paint from housing stock, we recommend that local efforts of the kind made in Paterson be encouraged. For one step in this direction, $50,000 should be allocated to study the sanitary codes in the state's municipalities and determine the costs of requiring pre-occupancy inspection of residences, enforcing current housing codes, and establishing a housing-risk registry.

Another $50,000 should be allocated to study lead poisoning of persons in publicly sponsored facilities (such as developmental centers for mentally retarded individuals, correctional institutions, and hospitals) and to determine the costs of removal and abatement of the sources of lead.

The remaining funds of $1,400,000 would pay for alternative safe housing, financial-aid programs, and our recommended research projects.

Secondary Prevention: $5,500,000 to Test Children

The New Jersey Department of Health estimates that 220,000 preschool children live in areas of the state that are high-risk areas for lead poisoning. However, the state has funds to test only about 23 percent of these children. The state uses a large percentage of the Maternal and Child Health Block Grant and *no state funds* for this screening.

Recently, $500,000 per year was appropriated to the Department of Health from the state's general funds for its lead program, to fund testing of children in high-risk areas. This small amount would have been used to keep afloat some model programs that have foundered on budget cuts, but no funds were actually been appropriated at this writing.

In the long run, if New Jersey wants to prevent lead poisoning, funds must actually be appropriated *each year* just to maintain the services that are offered now. What is more, much more will have to be appropriated for testing, treating, and following up thousands of lead-poisoned preschoolers whom the data suggest are now overlooked:

Test Every Child in High-Risk Areas for Lead Poisoning and Abate the Hazards of Lead

> Childhood lead poisoning is a major, totally preventable cause of learning disability and mental retardation [among] children in this state. It affects 3-5 percent of children in high-risk urban areas of the state.
>
> If the recommendations [of the Centers for Disease Control and of the Division of Maternal and Child Health] were followed to screen every child aged six months to five years of age on an annual basis, it is estimated that the cost would be $2.24 million for just the 20 percent medically indigent population [as shown in the accompanying tabulation].

CHILDREN	NUMBER
Aged 6 months-5 years	413,156
Currently tested	40,000
Not currently tested	373,156
Not currently tested, and medically indigent (20 percent)	74,630

> Costs per child for testing and follow-up are $30. To test the 74,630 medically indigent children would cost $2,239,000.]
>
> The distribution of the funds by sites would have to be worked out based on the distribution of the expected 74,630 medically needy, at-risk children not yet screened by the program. It is expected that these funds would be distributed to local health departments, two-thirds for new projects, and one-third to expand service areas in existing projects. If funds were limited to $500,000, the primary objective would be first to expand service areas within existing project cities, and then support county programs in [areas of high need] (Halpin 1985a).

In 1983, $1,300,000 was spent to screen 50,397 children. At that rate, the per-child cost is about $25. New Jersey should allocate $5,500,000 to screen every child in high-risk areas as the Assistant Surgeon General of the United States has recommended.

It was pointed out to the council that added expense would arise to improve laboratory capacity. (See our recommendation, "Immunize against Infectious Diseases" for comments on the need in New Jersey to improve diagnositic laboratories).

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CHAPTER 20

TEACH PARENTING SKILLS THROUGH FAMILY LIFE EDUCATION

RECOMMENDATION

Family life education has been shown to prevent many of the conditions of mental retardation that arise from lack of knowledge about family health, childrearing, and responsibility.

While family life education has been mandated in the state for the 611 school districts, fewer than 30 percent have included early infant and child care in their curricula.

A prenatal, perinatal and early child-care curriculum module that includes both the kinds of information needed to prevent mental retardation and a description of the resources available to teachers should be developed for teachers of family life education, health, and parenting classes.

This training module can be developed by the New Jersey Network on Family Life Education to be distributed without charge to family life education teachers and coordinators in each school district. A budget of $45,000 would cover the staff and activities of the program ($34,000) and printing and disseminating the modules ($11,000).

RATIONALE

Family Life Education Programs Ought to Train for Early Care

Since lack of proper prenatal care and lack of preparation for family life have been shown to cause so many disabilities, New Jersey has a law that requires programs for "family life education" in its elementary and secondary public schools. These newly-mandated programs provide an opportunity to reach all children with the kind of parenting education which could help in teaching prenatal care and care in early infancy.

The law requires family life education in each school district. Curricula are developed by local districts and may be updated and expanded as needed.

Out of 611 school districts in New Jersey, all have put some kind of family life education program in place, but only 30 percent have included prenatal and early infancy care components for pregnant teenagers.

Outside Expertise Needed

Curricula are developed and expanded in the local districts by their "curriculum development committees." Outside expertise can speed up their processes, which are often slow, owing to limited resources, and which have complicated legal and regulatory mandates to satisfy.

A prenatal, perinatal, and early-child-care curriculum module, which includes both the kinds of information needed to prevent mental retardation and a description of resources available to teachers should be developed for teachers of family life education, health, and parenting classes. This need is substantiated by responses that the New Jersey Network on Family Life Education network logged in the process of evaluating is statewide conference of 1984 and of keeping track of telephone calls to its offices.

The complexity of the conditions of mental retardation requires a multidisciplinary approach. A module for parenting education can best be developed through a compilation of information and resources from various resources.

Therefore, we recommend that a committee be formed, to include the Departments of Education, Health, and Human Services (Divisions of Developmental Disabilities and the Division of Youth and Family Services);

organizations that address mental retardation, such as the March of Dimes, the Association for Retarded Citizens, the Home Economics Association, the American Nutritional Education Association, the American Academy of Pediatrics, the office for Consumer Education of the University of Medicine and Dentistry of New Jersey-Rutgers Medical School; and organizations that are members of the New Jersey Network for Family Life Education.

This will ensure a module useful to social agencies and organizations, as much as to schools. For example, programs for adolescent pregnancy and parenting would find it especially helpful.

The office and staff of the New Jersey Network for Family Life Education can provide an appropriate home for this project since (1) all the relevant organizations are part of the New Jersey Network for Family Life Education; and (2) their offices and resources in the Center for Community Education at Rutgers University are equipped to handle this project. The Center for Community Education has had extensive experience with projects of this nature.

A TWO-YEAR PROJECT

Two years would be required to compile, write, and disseminate a curriculum through in-service training. A project director and a curriculum specialist would carry out these activities:

CONVENE A SPECIAL COMMITTEE

The project director will convene a special curriculum committee of volunteers from the relevant agencies who will design a model curriculum for prenatal and early infancy care that can be added to existing curricula for family life education.

COMPILE RESOURCES

The curriculum will include materials for appropriate grade levels, socioeconomic backgrounds, ethnicity, and gender; resources available to teachers through the various organizations represented; and commercially-prepared resources recommended by these organizations.

IDENTIFY A CURRICULUM SPECIALIST

An experienced teacher who can write well will write the curriculum and disseminate it as a trainer for school personnel.

DISSEMINATION

The curriculum for prenatal, perinatal, and early child care education will include resource listings from New Jersey to commercially prepared materials. It will be disseminated through eight regional workshops to be held in cities such as Trenton, Newark, Camden and Atlantic City. Prior to the in-service workshops, the project director or the curriculum specialist will schedule appearances at meetings of school administrators to prepare them for the development of the project.

COST ESTIMATE

This project would cost $68,500 for a two-year period, as shown in the accompanying tabulation.

	DOLLARS	
ITEM	**First year**	**Second year**
Total	**$51,000**	**$23,500**
Project director (full-time)		
Salary	15,000	15,000
Benefits	3,000	3,000
Curriculum Specialist (part-time)	15,000	—
Clerical (part-time)	5,000	2,000
Office	2,000	200
Printing	9,000	2,400
Meetings	2,000	900

CHAPTER 21

IMPROVE PROTECTION IN AUTOMOBILES

RECOMMENDATION

In 1983, about 4,000 New Jersey children were injured in motor vehicle accidents. The Charlottesville Prevention Council (1983) estimates that 60 percent of children who are injured in automobiles sustain trauma to the head and face, and that one in ten suffers brain injury. At that rate as many as 400 New Jersey children could be brain-injured each year.

The use of automobile safety restraints reduces both injury and death. A comprehensive program to promote the use of automobile safety restraints should be developed, including:

1. New Jersey's pioneering legislation that requires the use of auto safety restraints by all passengers in the front seats of automobiles should be extended to cover (a) the rear seat and (b) stronger enforcement and penalities.

2. A central office to coordinate and evaluate all programs (See our recommendation, "An Office for Prevention Programs.")

3 Loan programs for child safety seats

4. Public information campaigns

5. Community education programs

Annual funding in the amount of $64,860 would provide for the loan program for child safety seats and public information campaigns. We have not had the opportunity to develop cost estimates for an exhaustive, statewide community education campaign for the use of auto safety restraints.

RATIONALE

Accidents are a major cause of mental retardation. The President's Committee on Mental Retardation (1980) reports that

> ...accidents kill and injure more children in the United States than any other single cause...[and] the greatest number of accidents involves the automobile, which causes more deaths and permanent injuries from accidents than all other types of accidents combined.

Seat belts reduce both death and injury and enormous costs. Seat belts reduce the chance that a child will be killed or seriously injured by at least 60 percent, according to the Highway Users Federation and Automotive Safety Foundation (1984). The average costs for injuries and fatalities have been estimated to be $825-$12,340 in lost taxes; police, court, probation, medical examiner, and coroner costs; motor vehicle department, medical, hospital, welfare, and rehabilitation costs *(Ibid.)*.

New Jersey is probably already reducing injuries and gaining cost savings, even though use of seat belts is relatively new in its laws. Right now, the Office of Highway Safety estimates that 20 percent of persons use seat belts in New Jersey. As Table 21-1 shows, at that rate, the reductions and savings are already large. Table 21-1 presents the actual incidence of crashes and injuries in New Jersey in 1983 and the reductions in injuries and cost savings if seat belts are actually being used by 20 percent of persons. We can anticipate that the savings are much higher: in 1985, 40 percent of adults reported to the Gallup poll that they wore seat belts the last time they rode in cars (up from 25 percent in 1984), and New York reported a 27 percent decline in numbers of drivers and passengers killed in motor vehicle accidents in the first three months since the state's seat-belt law went into effect (New York Times, 9 May 1985).

Table 21-1. — Actual incidence and potential reductions in numbers and costs (millions of dollars) of fatalities and injuries in motor vehicle accidents, based on a 20 percent utilization rate of seat belts, for New Jersey, 1983

Type of crash and injury	Fatalities and injuries				
	Actual incidence		Potential reductions (a)		
			Reduced incidence		
	Number	Cost (b)	Percentage	Number	Savings (b)
Total, all crashes	**105,032**	**1,306**	N.A.	**11,697**	**155**
Injury					
Fatal	609	198	N.A.	109	35
Critical(d)	2,048	471	N.A.	216	50
Severe(e)	4,102	217	N.A.	433	23
Serious(f)	9,785	121	N.A.	1,087	13
Moderate(g)	19,601	109	N.A.	2,187	12
Minor(h)	68,887	190	N.A.	7,665(c)	21
Frontal impact crashes	81,969	1,059	N.A.	9,119	126
Injury					
Fatal	543	177	77	99	32
Critical	1,643	378	47	170	39
Severe	3,292	174	47	341	18
Serious	7,823	97	50	869	11
Moderate	15,670	87	50	1,751	9
Minor	52,998	146	50	5,889	16
Overturn crashes	1,692	34	N.A.	193	5
Injury					
Fatal	22	7	91	5	2
Critical	56	13	57	7	2
Severe	112	6	57	14	1
Serious	249	3	50	28	0
Moderate	499	3	50	55	0
Minor	754	2	50	84	0

Table 21-1. — Continued

Type of crash and injury	Fatalities and injuries				
	Actual incidence		Potential reductions (a)		
			Reduced incidence		
	Number	Cost (b)	Percentage	Number	Savings (b)
Angle and other crashes	21,371	213	N.A.	2,375	24
Injury					
Fatal	44	14	50	5	2
Critical	349	80	50	39	9
Severe	698	37	50	78	4
Serious	1,713	21	50	190	2
Moderate	3,432	19	50	381	2
Minor	15,135	42	50	1,682	4

SOURCE: New Jersey Department of Transportation 1984

N.A. means not applicable.

(a) Based on a utilization rate for seat belts of 20 percent
(b) Millions rounded to the nearest million
(c) Total for minor injuries for all crashes is not equal to the sum of the individual types of crashes
(d) "Critical injury:" must be medically treated in 1-6 hours or will be fatal
(e) "Severe injury:" must be medically treated in 7-24 hours or will be fatal
(f) "Serious injury:" must be medically observed for 24 hours.
(g) "Moderate injury:" must be treated at the hospital but on an out-patient basis
(h) "Minor injury:" simple cuts and bruises; no hospital medical treatment is needed

Although the child restraint law in New Jersey has been in place only since April 1983, there is already evidence of its effectiveness. The average number of fatalities for 1980-1983 in the aged group 1-4 years was 10.5 percent per year. The data for the first six months of 1984 show a reduction in fatalities by over 50 percent (assuming the number of children aged 1-4 years who were passengers has remained constant) (Schmitt 1984).

The use of seat belts is expected to increase. Table 21-2 presents the estimated savings to society at various rates of seat-belt usage.

Table 21-2. — Potential injuries avoided and cost savings, for different percentages of passengers who use safety belts, by the type of injury, for New Jersey, 1983

Injury	Percentage of passengers who use seat belts:					
	60 percent		80 percent		100 percent	
	Injuries avoided	Cost savings*	Injuries avoided	Cost savings*	Injuries avoided	Cost savings*
Total	**23,376**	**310**	**35,091**	**464**	**46,778**	**616**
Fatal	218	71	327	106	426	139
Critical	433	100	648	149	864	199
Severe	867	46	1,299	69	1,732	92
Serious	2,174	27	3,261	40	4,348	54
Moderate	4,376	24	6,561	36	8,748	49
Minor	15,308	42	22,995	63	30,660	84

SOURCE: New Jersey Department of Transporation 1984

* Millions of dollars rounded to the nearest million

Legislation for Automobiles and School Buses

Legislation is needed to protect more persons, especially children, who are at highest risk. The law in New Jersey already requires the use of auto safety restraints for children aged under six years and, as previously noted, for all drivers and front seat passengers in automobiles. The law, then, leaves children unprotected in the older age groups, in the back seats of cars, and in school buses, among other modes of transportation.

Since head injury can occur in the back seat of an automobile, we recommend that the law be extended to include this part of vehicles.

Central Coordination

Central coordination for programs for auto safety restraints already exists. The Office of Highway Safety in the Department of Transportation shares grant responsibilities with both the New Jersey Safety Council and the New Jersey Hospital Association. They have suggested some programs to increase access to seat belts among low-income populations and to educate the community about using seat belts.

LOAN PROGRAMS FOR CHILD SAFETY SEATS

To provide auto safety restraints to low-income populations, the Office of Highway Safety and the New Jersey Hospital Association propose a program to provide infant car seats to hospitals and health institutions, which would be lent to low-income families and out-of-state visitors who need to comply with the law that requires car seats for children aged under six years.

In New Jersey, 80 hospitals and health institutions have car-seat programs, but only 16 have started or plan to implement a loaner program. The Office of Highway Safety proposes a program in cooperation with the New Jersey Hospital Association. The office will provide 64 hospitals each with 10 infant seats for low-income new families and one "convertible" seat for out-of-state visitors. Each hospital will match the number of seats provided. At the time of the loan, a small deposit will be collected from each borrower, and most of this will be refunded on return. The balance is to cover clerical costs and pay for buying additional seats.

This modest proposal might be expected to meet the needs of about 1,200 new families each year in New Jersey (a rough estimate of the numbers of children affected).

PUBLIC INFORMATION CAMPAIGNS

Public education can build cooperative attitudes. One public education program proposed by the Office of Highway Safety is built on a design from the National Highway Traffic Safety Administration. The State Broadcasters' Association has agreed with the office to conduct an eight-week, incentive-based campaign. After five weeks of airing educational service announcements, 500,000 bumper stickers would be distributed for two weeks, customized with the call letters of 14 participating radio stations that reach a large market area. During four weeks, small prizes would be awarded to license numbers drawn at random from among those who are observed driving a car with a bumper sticker and who are wearing a seat belt. During the final two weeks, a grand prize of travel would be awarded.

A campaign such as this produces a large impression. For this model, 6,700 spots have to be donated by broadcasters (the commercial equivalent of

$168,000) and prizes have to be donated. It produces many messages: if each of the 500,000 bumper stickers were read by four people each day during the 50 days of the campaign, 100 million messages would be transmitted. A study in North Carolina by the National Highway Traffic Safety Administration shows that this technique does increase the use of seat belts (1982).

Costs are relatively modest, as shown in the accompanying estimate.

COST ESTIMATE

PROGRAMS	DOLLARS
Total	**64,860**
Loan Programs for child safety seats	19,860
Car seats-10 Century Infant Seats @ $20.00 and Century 200 Convertible Seat @ $40.00 for 64 hospitals	15,360
Training and monitoring	4,500
Public Information Campaigns	45,000
500,000 bumper stickers	35,000
Cash prize awards	10,000

COMMUNITY EDUCATION PROGRAMS

Changing attitudes about the use of auto safety restraints will have to come from more extensive education in the community of people who are at risk. These include

- Pregnant women
- Parents and guardians of children
- Health care providers
- Law-enforcement officials
- Civic and professional groups
- Employees in the public and private sectors

Model programs for such an education effort already exist. The Office of Highway Safety, the New Jersey Highway Users Conference, the New Jersey Hospital Association, and many other organizations have them on file.

We recommend an expansion of the community education component for auto safety restraints. We have not had the opportunity to develop cost estimates for an exhaustive, statewide campaign for the use of auto-safety restraints. Large-scale campaigns of this type could cost up to $1 million per year.

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CHAPTER 22

IMPROVE PROTECTION IN SCHOOL BUSES

RECOMMENDATION

While automobile safety restraints are growing in use to prevent injuries that may result in mental retardation, protection of children on school buses has been neglected. (See our recommendation, "Improve Protection in Automobiles.")

In 1977, the federal government adopted standards to improve school bus safety, but these have not had much effect. Strengthening the bus frame and installing well-constructed, well-padded, high-backed seats have not resulted in a great decline in injuries on board school buses (Yeager 1984). These standards neglect the problems of lateral collisions, when children may be thrust into unpadded areas; and of rollovers, which occur more often in school buses than in other vehicles because of the higher center of gravity of a school bus.

We recommend that all newly purchased school buses be equipped with safety belts for every occupant and with seats of a minimum seat back height of 28 inches. The New Jersey Legislature's Office of Legislative Services

estimates the cost of the new equipment at $1,200 per bus. Since a school bus has a life expectancy of 12 years and has seats for 66 passengers, the addition of safety belts and higher back seats would cost $1.50 per year per rider or 0.005 cent per rider per trip.

RATIONALE

Legislation Has Been Introduced

Legislation has been introduced to require safety restraints and high-backed seats in school buses. This legislation should be approved, we recommend that the governor sign it into law.

A New Jersey School Board Reviewed Arguments in Favor of Safety Belts

The School Bus Safety Belt Study Committee of the West Windsor-Plainsboro Regional Board of Education, compiled a list of arguments in favor, and against, the use of safety restraints on school buses. Their main arguments in favor of safety restraints are:

> 1. They prevent the passenger from being thrown from the seat in the event of sudden stops. Numerous injuries occur as a result of such incidents, even when the bus is not involved in an accident.
> 2. In conjunction with high- and heavily-padded seat backs, belts minimize the risk of whiplash injuries in fore and aft collisions.
> 3. For accidents that involve side impact, seat belts prevent the occupant from being unseated, an action in which the so-called "compartmentalization" effect of high seat backs alone appears to be of limited value.
> 4. The demonstrated benefits of using seat belts in automobiles would be replicated in buses.
> 5. Students trained to use belts in buses would be more likely to use them in automobiles.
> 6. Few, if any, of the drawbacks supposed by opponents have come about in those districts that use belts.
> 7. Installation of belts is inexpensive, amounting to about three percent of the cost of a full-size bus.
> 8. All buses built since 1977 have floor and seat structures with strength adequate to take seat-belt loads.

SUPPORT FOR THE ARGUMENTS IN FAVOR OF SAFETY BELTS

The Institute of Transportation and Traffic Engineering, University of California at Los Angeles conducted crash tests on school buses in the mid-1960s for the United States Department of Transportation. The researchers concluded that:

> These bus experiments, the many actual school bus accidents investigated by the authors, the many types of collision experiments conducted during the past 16 years by the authors and investigations by others, clearly establish the value in passenger protection of lap belts when used with high back seats. The greatest single contribution to school bus passenger collision safety is the high strength, high back safety seat. Next in importance is the use of a three-point belt, a lap belt or other form of effective restraint. These restraints can be added to the safety seat at very little added cost and their presence provides the continuity needed for proper training of youth concerning habitual use of restraints when riding in any vehicle (Severy, Brink, and Baird 1967).

The principal researcher, Severy, recently reaffirmed the conclusion of the study that seat belts in conjunction with properly constructed safety seats provide additional protection to school bus riders (Yeager 1984).

The United States Department of Transportation, acknowledging the low rate of the use of seat belts, asked the University of Southern California to conduct another series of tests to design a seat that, without the use of a seat belt, would provide greater protection to school bus occupants. The seat that was designed was *impractical* because of its massive size, but included a mesh, yielding back, 28 inches high, to absorb the impact of a crash and a heavy side arm to prevent lateral falls during a side crash *(Ibid.)*.

The Greenburgh School District in Hartsdale, New York, has had safety seats and seat belts on its school buses for five years. The director of pupil transportation there reported that *the number of head and neck injuries has declined since the installation of the safety equipment* (West Windsor-Plainsboro Regional Board of Education 1984).

What the West Windor School Board Committee Reports about Safety Belts in School Buses

ACCIDENT AND INJURY STATISTICS ARE MISLEADING

It is misleading to assert that school buses are much safer then automobiles.

The accuracy of the statistics reported to the National Safety Council is questionable since in its own disclaimer in "Accident Facts," the National Safety Council notes "the states are inconsistent in how and what they report regarding accidents, injuries, and even deaths, and that underreporting is widespread" (Fast 1984).

"COMPARTMENTALIZATION" (A PROPOSED ALTERNATIVE) LEAVES TOO MANY CHILDREN UNPROTECTED

Adequate protection for children in school buses is not achieved through current "compartmentalization."

The seat designed by the University of Southern California embodied the idea of compartmentalization, but this is not the seat we find on school buses today. The 1977 standards have resulted in seats that are well anchored and well padded. However, raising the seat height only to 24 inches — the point at which 60 percent of the potential school bus riders would be below the top of the seat (New Jersey School Boards Association 1984) — *leaves 40 percent of school bus riders at risk for injuries when a bus is hit in the rear.* Moreover, there is no protection in lateral crashes and rollovers when children are thrust into unpadded areas of the bus.

SEAT BELT USE CAN BE MONITORED AS ARE MANY OTHER ACTIVITIES ON SCHOOL BUSES

As stated before, the districts that currently have seat belts in school buses report high use rates. In Greenburgh, New York, the usage rate is 80 percent, with almost 100 percent compliance by elementary school children (Schwartz and Klenetsky n.d.). This district does not use monitors on its school buses, the bus driver is the only adult on board.

Ardsley, New York, has seat belts on its school buses, too. Ardsley has monitors on the buses for grades kindergarten through eighth (Fast 1984).

The Greenburgh district instituted the use of seat belts by involving (1) teachers through lesson plans and course content, (2) parents through periodic monitoring of buses, (3) well-trained bus drivers through their insistence that children use the seat belts properly, and (4) school administrators through their disciplinary authority over those who do not use the seat belts. According to Fast (1984), the district claims about an 80 percent use rate *(Ibid.)*.

LAWS ALREADY PROTECT DRIVERS AGAINST UNWARRENTED LIABILITIES

Drivers and school districts would not incur additional liability if a student were injured as a result of not wearing a seat belt when one was available. The law could be written in language similar to legislation for auto safety restraints for children. The law could state that failure to use seat belts provided in school buses would not be considered a negligent act and would not be admissable as evidence in a civil suit (Yeager 1984).

States might be more worried because of a trend to file suits because of *lack* of seat belts on buses. Parents in Texas whose son was fatally injured in a school bus are suing the bus manufacturer for *not* providing seat belts. In Arizona, a school district is being sued by a girl who became paralyzed in a rollover accident for not providing belts (Schwartz 1984).

USING SEAT BELTS WILL NOT DELAY THE BUS

Buckling and unbuckling seat belts are fast procedures. With instruction about the proper use of belts and enforcement of the rules, schedules should not be delayed.

CHILDREN CAN BE TAUGHT TO USE SEAT BELTS

Concern has been expressed about whether young children would be able to work the buckles or adjust the belt length. Children can be taught to use the seat belts properly. Some districts have used portable training devices before installing belts on the buses *(Ibid.)*. Volunteers or paid monitors could ride on the school buses to assist young children when the safety belts on buses are introduced. Teachers could describe the proper use of belts with the aid of a video presentation.

SEATS BELTS ARE NOT HAZARDOUS

PLASTIC BUCKLES ARE NOT WEAPONS

The safety belts installed in school buses have lightweight plastic buckles — not very good "weapon" material. Fast (1984) reports that in the several districts with seat belts in their large buses, there has been no case of use of the belt as a weapon.

INSTALLED SO NO ONE CAN TRIP

Opponents of seat belts on buses argue that the belts would present a hazard by being on the floor and causing students difficulty in walking. This simply is not true. The belts are installed so the short end is on the aisle and cannot hang down to cause tripping.

NOT VERY CONFUSING TO CHILDREN

Experience has shown that confusion of which belt to use is a minor problem that can be solved by color coding.

INTERNAL INJURY IS NOT LIKELY

Opponents of seat belts on school buses claim that seat belts can cause internal injury, especially to small children. Medical experts do not support this assertion. Among those organizations that strongly favor safety belts on school buses are the American College of Preventive Medicine (Kane 1984), the American Academy of Orthopaedic Surgeons (Nelson 1984), the Center for Automotive Safety (Ditlow 1984), the American Association for Automotive Medicine (Petrucelli 1983), Physicians for Automotive Safety, and the American Academy of Pediatrics (West Windsor-Plainsboro Regional Board of Education 1984).

States (1983), writes that children are better able to withstand trauma to the spine, abdomen, and pelvis, particularly that applied by a lap belt, than are adults. In response to whether seat belts on buses could be hazardous, States said he knew of "...only one instance of over 3,000 accident investigations of which I have conducted, where a safety belt did cause more severe injury than would have occurred without the belt. This injury occurred to an adult and not a child" (States 1983).

RAPID ESCAPE

Opponents of school bus safety belts claim that, in the event of fire, seat belts would prevent rapid escape. This is doubtful. The National Transportation Safety Board has investigated two rollover accidents in smaller school buses that have had seat belts in them since 1977. In both instances, very young children were using seat belts and were able to unbuckle themselves easily while hanging in the air because of the accidents. There were no injuries (Fast 1984).

$1.50 PER CHILD PER YEAR

The claim that seat belts are expensive is untrue. The New Jersey Office of Legislative Services estimates that $1,200 per bus would comply with the safety standards. This amounts to $1.50 per year per pupil per school bus.

As seen in Table 22-1, the cost to the individual districts would be minimal, since most of the cost would be reimbursed through state aid. The estimated cost to all the school districts in New Jersey (after state aid reimbursement) to replace, during a three-year period, more than one-fourth of the bus fleet with the safer buses mandated in recent legislation in New Jersey is only $181,240.

Table 22-1. — Estimated dollar costs to the school district and state aid reimbursement, by year, for installing safety belts and 28-inch high-backed seats in school buses, for New Jersey

Year	Dollars	
	Cost to the school district	State aid reimbursement (two-year lag)
1	477,600	429,840 (year 3)
2	570,800	513,720 (year 4)
3	664,000	597,600 (year 5)

SOURCE: New Jersey State Legislature 1984

Note: These estimates use the following assumptions and data:

1. Number of school buses in use: 12,900 (8,800 Type 1 large, 4,100 Type 2 van)
2. Ownership: 60 percent private fleet contractor, 40 percent school district
3. Service life: 12 years for Type 1, 10 years for Type 2
4. Annual replacement schedule: 733 Type 1 vehicles, 410 Type 2 vehicles
5. Private operator costs amortized to school district over life of vehicle
6. Cost of compliance: $1,200 for Type 1 vehicles, $200 for Type 2 vehicles (Type 2 vans have had seat belts by federal requirement since 1978.)

The costs to the school district for installing safety belts and high-backed seats were calculated by assuming that of 733 Type 1 vehicles scheduled to be replaced each year, 293 were owned by the districts and 440 were rented by the districts. Replacing the owned buses with safer buses would cost the school districts an additional $1,200 per bus at the time of purchase. However, the extra expense of $1,200 for the rented buses would be amortized over the 12-year life of the bus.

A similar assumption was made regarding annual replacement of Type 2 vehicles, with 164 district-owned and 246 rented. The replacement of owned vehicles with the safer buses would cost approximately $200 more per bus while the extra cost to replace rented vehicles would be amortized over the 10-year life of the vehicle (Kooney 1985).

Safety Belts and High-Backed Seats Should Be Installed on All Newly Purchased Buses

We recommend that all newly purchased school buses be equipped with safety belts for every occupant and with seats with a back of a minimum height of 28 inches. To increase the safety of our children while in school buses, we strongly urge the governor to support legislation for this.

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CHAPTER 23

APPENDIX

IDENTIFY PEOPLE WHO ARE DISABLED OR WHO ARE "AT RISK" AND ENCOURAGE NEW AND EXPANDED SERVICES

Two problems arose recurrently in the discussions of the council: the problem of how to identify people who are in need of services and document their needs, and the problem of how to encourage new and expanded services.

Some innovative suggestions for addressing these problems came to the council in the form of proposals for programs. We present these here to illustrate (1) how prevention programs have to cut across te conventional boundaries of established programs; (2) how advanced are the resources that New Jersey can call into action for setting up prevention programs; and (3) how crucial is the need for a structure in government that can see that prevention programs find support and funding.

IDENTIFYING PEOPLE AND DOCUMENTING NEEDS FOR SERVICES

First, planning has to account for two groups of persons who are in need of services:

1. People who are disabled: any group that we can identify by a handicapping condition
2. People who are "at risk" of developing a handicap (urban and rural low-income and minority families, for instance)

More is known about those who are disabled than about those who are at risk. The dimensions of the problem are suggested by the accompanying list.

THOSE WHO ARE DISABLED	THOSE WHO ARE "AT RISK"
1. Need to be identified	1. Risk factors need to be defined
2. Need earlier referral to services that are in place	2. "Outreach" efforts must be developed
3. Services are available but may need improvement	3. Services have to be designed
4. Limited in number	4. Many in number
5. Potential costs can be defined by projections Based on current services	5. Potential costs have not been determined

To make sure that appropriate programs are developed and can be justified, needs for services have to be documented by specifying numbers of persons, localities, services already in place, and so on.

ENCOURAGING NEW AND EXPANDED SERVICES

Second, the problem of how to encourage new types of services arises from the fact that there is a network of "operating agencies" (health-care providers and social agencies) who provide services for both those who are disabled and those who are at risk. These agencies need to provide new types of programs to reach both those who are disabled and those who are at risk and need to be encouraged to do so.

These two problems came to the attention of the council in the form of proposals for recommendations. We discuss them here in the order shown in the accompanying list.

Identify people and document needs for services
1. Low-income families
2. Persons who are "dually diagnosed"

Encourage new and expanded services
3. Operating agencies
4. Hospitals

1. IDENTIFY PEOPLE "AT RISK": LOW-INCOME FAMILIES

The largest group that needs to be identified are low income families and their children who live in urban and rural areas. These families are generally thought to be at comparatively greater risk of mental retardation.

Those whose families have incomes below the level of poverty are more likely to be subject to organic risk factors such as preterm births, malnutrition, lead poisoning, prenatal diseases and infections, and learning disabilities.

We know that these organic conditions are worsened by poverty because when we cut back programs that address poverty, infant mortality rises. Causes of infant mortality closely parallel the causes of mental retardation.

After years of a continuing decline in the infant mortality rate, the decline has slowed abruptly. This change coincides with cutbacks in federal programs that reach low-income mothers and children: family planning, basic health services, and nutritional programs. Mortality rates for wealthy children were 42.5 percent *lower* than mortality rates for poor children in Boston, where 93 percent of all births occurred in perinatal facilities with neonatal intensive care units (Wise *et al.* 1985).

Further, people with incomes below poverty are more likely to be subject to non-organic risk factors, such as a non-stimulating early environment. Socioeconomic status, gender, and maternal and paternal educational levels are some of the variables that predict intellectual functioning and suggest the influence of the environment (Siegel 1985).

The Governor's Committee on Children's Services Planning reports that at least 45,000 children aged 3-5 years have family incomes below the level of poverty and live in depressed, segregated, overcrowded, and unsafe housing (New Jersey Governor's Committee on Children's Services Planning 1985) in New Jersey.

Children from Low-Income Families Are Not So Likely to Do Well in School

Children from low-income families are more likely to be classified by officials as "educable mentally retarded." The Cantalician Foundation summarizes the problem in this way:

> There are more, often many more, minority students in special education programs for educable mentally retarded students than would be expected if predictions were based solely on the proportion of minority students in the community. This...disproportion...is neither a new nor an isolated phenomenon and it is especially true for black children. For example, the 1980 Office for Civil Rights'...biannual nationwide survey of students revealed that while 16 percent of all elementary and secondary students in this country are black, 39 percent of the students in classes for the [educable mentally retarded] are black. The proportions vary from place to place, but the overall pattern is clear (Cantalician Foundation n. d.).

In New Jersey, the Department of Education has documented a decline in the numbers of children who are classified as "educable mentally retarded," but their data show that these children are simply being reclassified as "perceptually impaired" (New Jersey Department of Education 1984b). Local school districts carry out this reclassification, perhaps to avoid stigmatizing children, to promote upward mobility, and to meet demands for "improved performance."

There Are "Early Intervention" and Preschool Programs for Children Who Are Classified Disabled

There are programs in the Departments of Health, Human Services, and Education for special education, for disabled children who are aged 0-3 years (early intervention), and for older preschoolers who can be classified *handicapped or potentially handicapped.*

For instance, New Jersey's early intervention program sets up these eligibility criteria:

> 1. A child must display a condition that impairs "normal attainment of developmental milestones."
>
> 2. A child must have measurable delays or disordered behavior in two or more of the following developmental areas: (a) gross motor,

(b) fine motor, (c) communication, (d) sensory, (e) cognitive, (f) social-emotional, (g) self-help, and (h) self-feeding.

Similarly, preschool education programs are supposed to be developed for older children who are defined as (1) auditory handicapped, (2) chronically ill, (3) communications handicapped, (4) emotionally disturbed, (5) educable or trainable mentally retarded, (6) multiply handicapped, (7) neurologically or perceptually impaired, (8) preschool handicapped, (9) orthopedically handicapped, or (10) visually handicapped (NJAC 6:28).

Similar Programs Should Be Developed for Children Who Are "At Risk"

One of the better researched phenomena within education has been the well documented results of working with preschoolers. A rate of classification of mental retardation that is 20 percent lower than classifications for comparable children; better school achievement; higher employment; and fewer social problems, such as crime and welfare dependence, have been documented.

Designed for children who have been identified as "at risk" because of economic, social, and cultural conditions, preschool programs have been able to alter the cycle of educational failure. After 20 years of research, Berrueta-Clemont (et al. 1984) documented these effects. Children who went through Weikart's Perry Preschool Project, as compared to peers who did not, have a significantly higher rate of completing high school, college, and job training, in addition to the 20 percent lower rate of classification as mentally retarded.

Findings show that preschool programs do not necessarily have to be elaborate comprehensive programs that include the whole family. Weikart points out that the components of success are a well-developed curriculum, supervision, in-service training, continued evaluation, and a strong support group. The Carolina Abedcedarian Project (Ramey and Haskins 1981), a longitudinal research effort, has documented benefits to IQ, adaptive behavior, social adjustment, and language development. (See Manni, Winikur, and Keller [1984] for a summary.)

Identify the Need for Services

The numbers of children who are at risk of mental retardation owing to conditions of poverty could be quite large. A rough estimate of the numbers of children at risk is shown in Table 23-1.

Table 23-1. — Children, aged 5 years and under, related to the head of the household, in families with 1979 incomes below poverty, for New Jersey, 1980

Age (years)	Number of related children	
	All children	1979 income below poverty
Total	**548,348**	**91,654**
Under 3	276,793	46,525
3 and 4	180,078	29,974
5	91,477	15,155

SOURCE: United States Department of Commerce n.d.

A Cooperative Project

One panel has estimated that "60 to 70 percent of the children who are now labeled as mildly mentally retarded, especially those from lower socioeconomic levels and ethnic minorities, would never be referred, labeled, and placed if appropriate educational strategies were available" (Mercer 1983).

We recommend that:

A. Services for infants and preschoolers who are not handicapped but who are at risk should be developed by collaboration among the Departments of Human Services, Health, and Education, much as they have collaborated on early intervention and preschool education of the handicapped.

B. An assessment should be made of the public and private operating agencies that already reach infants and preschoolers in the state. The expertise of Head Start and of preschool programs and personnel should be called upon.

C. An early childhood family-parent support program should be designed to include a preschool education component with strong curriculum, teacher training and supervision, and evaluation.

D. Once the assessment has been completed, cooperative planning should be encouraged among preschool programs, the local school districts, and the departments concerned to assure that early intervention programs reach the populations in need and to assure testing, evaluation, and dissemination of the results.

E. This program should be extended, at a minimum, to reach every infant and preschool child in the state whose family income falls at or below poverty.

2. DOCUMENT NEEDS FOR SERVICES: PERSONS WHO ARE "DUALLY-DIAGNOSED"

Little attention has been given to the problem of *preventing* the development or reducing the impact of emotional disturbance in retarded persons. Mentally retarded persons are at a *substantially greater risk* for emotional disturbance than persons in the general population (Lewis and MacLean 1982). Some recent estimates put the prevalence of psychiatric disorder at four to five times that seen in non-retarded groups (Matson and Barrett 1982).

It is difficult to characterize the physical and emotional costs that result when the mental health needs of retarded persons go unmet or are inappropriately addressed. *It is clear, however, that the most frequent reason for institutionalization, re-institutionalization, or inappropriate placement is aberrant or inappropriate behavior.* Even though the Family Court Act forbids the placement of mentally retarded children and youth in municipal, county, and state *correctional* facilities, they continue to be placed there for lack of proper diagnosis and alternative services.

Emotional disorder among mentally retarded persons is *difficult to diagnose*. Conventional assessment and diagnosis rely on language. This skill may be limited or non-existent among mentally retarded persons.

There is little information available on the subject of emotional disorder in mental retardation (Matson 1982; Szymanski and Biederman 1984) despite conclusions that depression (for example) may be "pervasive" among retarded clients (Matson and Barrett 1982).

There is a *lack of adequately trained* professionals to deal effectively with the problem (Gualtieri 1979).

Mental retardation services are separated from the mental health service delivery system.

The problem is centered in *inadequate and conflicting classifications*. To give a few examples:

(1) "Special education" classifications do not permit us to say how many New Jersey "special education" pupils may also be "emotionally disturbed." Some school districts use this classification only when a psychiatrist diagnoses a child. Others apply the label "emotionally disturbed" when the child's behavior becomes too difficult to manage in the classroom. Further, when the diagnosis "emotionally disturbed" is made, the case is grouped under the general category, "multiply handicapped," which can refer to a wide variety of possible diagnostic combinations.

The services that school districts provide suggest a wide prevalence, however. An inquiry into the population served by one school district of 4,000 students revealed that approximately 20 percent of the mentally retarded population served have significant emotional problems that have required special programming, such as placement in a private school.

(2) Classifications used for *"mental retardation"* by the Department of Human Services are similarly vague. An inquiry into the population at Woodbine Developmental Center revealed that about 25 of the 758 residents, or approximately 3.5 percent, had a "psychiatric disorder." The Division of Developmental Disabilities wished to, but could not, provide the council with data in which it would report on the number of persons in state psychiatric facilities who are labeled as mentally retarded, and on the number of persons in the mental retardation institutions, and community placements who have been identified as having major psychiatric impairment. The American Psychiatric Association has recently revised its diagnostic and statistical manual in a major way. It will take time to clarify how its categories are to be applied to people who have both mental retardation and psychiatric symptoms.

Gross characterizations can be made. For example, there are large numbers of residents who have serious "behavior problems" (such as head banging and ruminating), and who have received psychotropic medication, yet who do not have a major psychiatric diagnosis.

The rate of use of psychotropic drugs in residential and community placements suggests that cases of "dual diagnosis" may be many. Psychotropic drug use in institutions ranges 20-70 percent (Sprague and Baxley 1978). Prevalence among persons in the community has not been carefully studied, but, according to recent reports, does not differ markedly from rates among people in residential placement.

However, a large percentage of the psychotropic medication orders written for retarded persons are for antipsychotic drugs, sometimes referred to as major tranquilizers (Rivinius 1980). Antidepressant or anxiolytic agents are prescribed far more frequently than antipsychotic compounds for persons who are not mentally retarded. This suggests that mentally retarded persons who have effective disorders are not being identified or treated.

A Multi-Agency Task Force

So little is known about the relation of emotional disturbance to mental retardation that people who are already affected should be assessed in terms of their needs for services. By defining who is dually diagnosed, what the diagnoses are, and what services are needed, we can learn to identify the condition earlier in its development and prevent it at younger ages.

To address this problem, we recommend the establishment of a multi-agency task force to include the Department of Human Services (Divisions of Developmental Disabilities, Mental Health, and Youth and Family Services); the Department of Education (Division of Special Education); the Department of Health; and the Association for Retarded Citizens, among other community agencies. The task force should adopt the following objectives:

1. Establish diagnostic procedures
2. Determine the prevalence and incidence for different social and biological factors
3. Train professionals, stimulate research, and promote the coordination of prevention efforts
4. Institute pilot programs to implement prevention methods

At present there are no coordinated programs in New Jersey aimed at identifying, treating, or preventing emotional disturbance in mentally retarded persons. To our knowledge, such programs are not available elsewhere. However, some efforts have already been made to begin working with this population on a very limited basis.

Programs for people with dual diagnosis can be established in mental health facilities. The problem of dual diagnosis has been addressed in a limited way by the establishment of the development center at Ancora State Hospital. This needs to be accompanied by a broad initiative. For instance, community mental health centers can cooperate with private schools. One private school administrator whom we interviewed indicated that at his school, professionals from the local mental health center work with the staff on ways to treat behaviorally disturbed mentally retarded students. Again, community mental health centers can cooperate with the Division of Developmental Disabilities in creating appropriate placements.

The Division of Special Education can cooperate with private organizations to meet the special needs of this population, perhaps on the model of the Council of Organizations and Schools for Autistic Children (COSAC).

Cost Estimate

A program such as we recommend might begin with a task force that would develop definitions, procedures, and information on models programs in other states.

Clients who exhibit emotional disturbance, particularly if this involves disruptive or aggressive behavior, require costly programs with large numbers of staff. Other costs may include physical injury or property damage. The cost of managing clients who exhibit behavior disorders goes beyond fees for residential placement. Beyond physical injury or property destruction is the personal suffering associated with such emotional disorders as depression or severe anxiety, as well as their effect on the family. These costs cannot be measured.

More mental health services for retarded persons could decrease the use of costly institutionalization, private school, and private day placements, and the immeasurable emotional damages of personal suffering.

3. ENCOURAGING NEW AND EXPANDED SERVICES: THROUGH THE OPERATING AGENCIES

Many persons who are disabled are at risk for exacerbation of their conditions because they are not known to the agencies that are set up to provide the services that they need. The council received a proposal for a needs-assessment survey that illustrates this problem.

Cerebral Palsy

Cerebral palsy is a condition in which emotional and behavioral problems may occur owing to a physical disability, and 65-70 percent of persons with cerebral palsy are mentally retarded. Cerebral palsy is a group of neurological conditions that results in impaired or abnormal functioning in the areas of the brain that control movement. The disorder includes difficulty with muscular and sensory functions and may or may not be associated with mental retardation and seizure disorders. People with cerebral palsy may have difficulty in mobility, speech, and activities that require a high degree of muscular coordination.

The population of persons with cerebral palsy is largely uncounted. About 700,000 Americans are supposed to have some form of cerebral palsy. The New Jersey Developmental Disabilities Council estimates (1983) that there are 75,650 persons with various disabilities in the state. One estimate is that cerebral palsy affects 1.5-2.0 persons per 1,000 live births. At that rate, there would be 11,000-15,000 persons with cerebral palsy in New Jersey, or 14-15 percent of the developmentally-disabled population (United Cerebral Palsy 1984).

Even at one-half this rate, however, persons with cerebral palsy are probably largely underserved in several ways.

First, there are *too few operating agencies.* United Cerebral Palsy of New Jersey serves about 1,000 clients through five agencies (East Orange, Hudson, Union, Monmouth-Ocean and Cumberland-Salem), and other agencies serve about 800 persons with residential, early intervention, day, special school, and adult programs.

Second, *diagnoses are inadequate.* Persons in state institutions may have a primary diagnosis of mental retardation or of cerebral palsy for lack of adequate diagnosis. Inadequate diagnoses may lead to inappropriate services.

Third, *programs are inadequate or inappropriate.* The few agencies that operate programs do not have comprehensive programs that cover the continuum of needed services — residential, early intervention, day programs, special schools, and adult programs. There are many residents of skilled nursing homes who are placed there only because of cerebral palsy and who are inappropriately placed. There are no programs or services for adults with cerebral palsy who are mentally retarded, so these persons are even more at risk for emotional and behavioral disabilities.

DATA ARE NEEDED TO DOCUMENT NEEDS

More data are needed to develop primary and secondary prevention. First, as to primary prevention, any increase in knowledge of persons who are in a population of the disabled can be used to increase the whole range of general health services to *the disabled and to their families.* Second, the same process can increase secondary prevention to the disabled. There appears to be a very long delay between the diagnosis of cerebral palsy and intervention, a delay the causes of which probably are imbedded in the whole organization of the society around the affected population.

This research and documentation has to be encouraged from outside the community of the affected and the operating agencies. The affected need to develop the power to represent themselves. The agencies that serve them, all about 35 years old, have had a history of emphasizing direct fund-raising, and this has naturally curtailed the development of services.

PROPOSAL FOR A NEEDS ASSESSMENT

United Cerebral Palsy proposed to the council that it study a sample of its 1,000 clients. Over a two-year period, two research staff would carry on research aimed to establish baseline data and to develop ways to decrease the time from diagnosis to treatment. Clients and their families, residents of institutions and nursing homes, and others as discovered would be surveyed for socio-demographic data, enumeration, evaluation of current services, and determinations of needs for services in the future.

The cost of survey work would amont to about $100,000 for a two-year period. Since United Cerebral Palsy estimates that some $3.75 billion is spent each year nationwide to care for persons with cerebral palsy, any documentation of needs for services likely to promote earlier intervention would probably be cost-beneficial for New Jersey in the long run.

4. ENCOURAGING NEW TYPES OF SERVICES IN HOSPITALS

The council received two suggestions about services in hospitals. One is a proposal to encourage more refined measurement of data on the newborn. A second is a proposal for a community education program.

4a. Technology to Measure Neonatal Jaundice

We received a detailed proposal for the early detection of neonatal jaundice, but the structures needed to implement the proposal remain to be identified.

A BLOOD PRODUCT KNOWN TO CAUSE IRREVERSIBLE BRAIN DAMAGE

Bilirubin, a breakdown product of hemoglobin, is a known neurotoxin, which, under certain conditions and when present at sufficiently high levels, is able to penetrate the blood-brain barrier and cause serious neurological damage, such as deafness and death (kernicterus). While the neurological consequences of hyperbilirubinemia, particularly the long-term effects, are complex and imperfectly understood (Maisels 1983), the risk of irreversible brain damage increases with serum bilirubin levels and with levels of "unbound" bilirubin in the blood (Cashore and Oh 1982; Pledger, Scott, and Belfield 1982).

Hyperbilirubinemia of the newborn is a condition that is frequently encountered, particularly in low-birthweight and premature infants.

CONVENTIONAL MEASUREMENTS NOT SATISFACTORY

Today, *total serum bilirubin* levels are routinely measured in most neonatal hospitals to see if they exceed certain levels. The levels that are considered tolerable are arrived at by experience; and when they are exceeded, "phototherapy" and, in serious cases, "exchange transfusion" are recommended (Maisels 1981).

Evidence has accumulated that total serum bilirubin level is not, however, a sufficiently sensitive indicator for the risk of brain damage. It has been suggested that measuring ***unbound bilirubin*** levels, or the blood's reserve capacity for binding bilirubin, may be valuable in the management of jaundiced neonates (Pledger, Scott, and Belfield 1982). Such measurements were, until recently, difficult, time-consuming and expensive to obtain, and remained confined to a few specialized clinical laboratories, for research studies.

A NEW MEASURING INSTRUMENT

A new instrument has been developed to make these more accurate measurements without undue expense, time, or difficulty; but it is not yet in general use in neonatal centers. This semiautomatic instrument, the bilirubin hematofluorometer, which was developed by AT&T Bell Laboratories, has been approved by the Food and Drug Administration, and is produced in New Jersey. The instrument measures bound and total bilirubin and reserve binding capacity of bilirubin in microquantities of blood (Lamola *et al.* 1979).

THE BEST AVAILABLE INDICATOR FOR TREATMENT

This instrument provides the best available measures for treatment. First, its measurements have been shown to be in accord with the results of the more expensive, time-consuming, and difficult laboratory measurements in several clinical studies (Cashore et al. 1980; Brown *et al.* 1979; Wells, Hammond, and Lamola 1982). Second, the measurements based on binding parameters that the instrument gives correlate with treatment categories that take into account birthweight and total serum bilirubin at different postnatal times (Lamola and Faranoff 1984).

While risk for brain damage depends on many factors, the measures available from the hematofluorometer offer the best available means to determine appropriate management for a neonate that can be obtained from an assay of the blood performed in a neonatal nursery.

COST ESTIMATE

Funds to supply the equipment ($42,500) and to administer the program would be needed. Measurements with this instrument will make it possible for pediatricians to select the least risky therapy for all newborns. This should result in cost savings, since the length of the hospital stay of at-risk newborns is likely to be reduced as a result of new information. Beyond that, the care of seriously jaundiced infants is likely to be improved and the risk of brain damage reduced. Again, one outcome of necessary follow-up studies would be to improve the strategies for hospital treatment of jaundice in general.

4b. Community Education through Hospitals

The New Jersey State Health Care Council has already documented in detail how all New Jersey hospitals are long on specialized services offered on a statewide or regional basis, short on secondary care offered on a subregional basis, and shortest on prevention and health promotion services. Their conclusion is that hospitals should be encouraged to develop prevention and health promotion services in their local communities (New Jersey Department of Health 1982).

In the course of developing its recommendation, "Educating Persons at Risk About Alcohol," the council received an innovative proposal for a program of community education from a hospital in Essex county.

Essex county is an area of exceptional need in the state. This is the county of highest risk. This county has the highest number of births and the highest number of births to mothers aged under 19 years, of low birth weights, and of alcoholic women in treatment.

So extensive is the population and the problem in this county that the resources of many hospitals and related health programs will have to be broadened to reach the population at risk. There are two Essex level III perinatal centers, Newark Beth Israel and University-United hospitals. The countywide catchment area is much broader than they alone could serve with community education and training programs. In Essex, as in other counties, community-oriented general hospitals should develop community education programs to reach populations at risk.

East Orange General Hospital has designed a demonstration project to train health-care, human services, and education workers in 50 agencies through the hospital's Department of Alcoholism Services. This program would utilize and expand the community linkages that the hospital has established over eight years through providing alcoholism detoxification and rehabilitation, outpatient services, and 24-hour-crisis-emergency services.

The program comes from proven models. The model has been tested successfully at the Eunice Kennedy Shriver Center for Mental Retardation in Massachusetts (Oullette 1983); and a Boston study of physician education of this type showed that programs such as this reduces the number of cases of infants reported with mental retardation (Rosett *et al.* 1978). Detailed guidelines for the program have been prepared by the state of Michigan in a joint effort among the Departments of Education, Public Health, Mental Health, Social Services, Substance Abuse, and Highway Safety.

On a local level, this project, coordinated and operated out of East Orange General Hospital, would have the cooperation of local health departments, agencies, physicians, nurses, parents, schools, and the clergy, who have recognized East Orange General Hospital as a pioneer in providing health services responsive to the suburban Essex county community.

COST ESTIMATE

The program would cost about $55,000 for a one-year period, including three staff, logistic support, and evalution.

The council voted to recommend this demonstration pilot program for suburban Essex county, which is designed to use the training of professionals to reach out to people in the community at large, in the work place, in school, and at home. A model program, such as this, can be put in place quickly, evaluated, and reported so that other community hospitals can replicate the work with reduced research and start-up costs.

Summary

Our recommendation for an Office for Prevention would provide a mechanism to develop these programs to identify new populations and develop new and expanded services. Each requires the research, public information and education, coordination, and executive action that only such an office could develop.

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